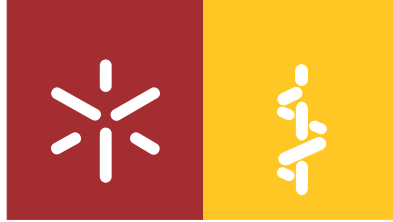




Universidade do Minho
Escola de Medicina

Rogério João Mulumba

**Characterization of Burnout in the
Informal caregivers of patients with
Mental Illness**



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Informal caregivers of patients with
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Dissertação de Mestrado
Mestrado em Ciências da Saúde

Trabalho efetuado sob a orientação da
Doutora Nadine Correia Santos
e do
Professor Doutor Pedro Luís Morgado

julho de 2017

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particularmente nos de incerteza, muito comuns para os sonhadores.
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ABSTRACT

Introduction: Burnout is a psychological syndrome characterized by the presence of emotional exhaustion, attitudes of depersonalization or cynicism, and feelings of lack of personal fulfillment. It is mainly present in individuals who have a professional, social or voluntary responsibility or task of dealing or caring for others. **Objectives:** Characterization of burnout and identification of its risk factors in a population of Informal caregivers of patients with Psychiatric disorder (ICPPD) using as control the Informal caregivers of patients with Non-Psychiatric disorder (ICPNPD). **Materials and Methods:** The sample of informal caregivers consisted of 80 individuals interviewed at the Braga Hospital and Casa de Saúde do Bom Jesus (Braga, Portugal); half were ICPPD and half ICPNPD. To evaluate Burnout the Maslach Burnout Inventory – General Version was used, and for the evaluation of stress, stigma and coping strategies the scales PSS-10, AQ27 and CAMI were used, respectively. **Results:** The ICPPD had significantly higher levels of Burnout in comparison with ICPNPD, being moderate in ICPPD (mean = 1.91, SD = 1.12) and low in ICPNPD (mean = 1.41, SD = 0.91). The percentage of caregivers with burnout was higher in the group of ICPPD (65%) compared to the group of ICPNPD (42%). Stress had a significant impact on the Burnout linear regression model in ICPNPD compared to ICPPD. The effectiveness of the coping strategies had more impact on the burnout of ICPPD compared to ICPNPD, and the Psychiatric Disorder stigma perceived by the ICPPD had no effect on their burnout levels. The female gender and the elevated number of readmissions were associated with higher burnout levels in the ICPNPD. The high degree of patient dependence on the instrumental activities of daily living, the younger patients, the presence of chronic illness in the caregivers, or the long period as a caregiver significantly increased Burnout levels in the ICPPD compared to the ICPNPD. **Conclusions:** There is a need to provide caregivers with the necessary tools to deal with the difficulties in their task, particularly female caregivers, those who have a chronic disease, those whose patients have elevated number of hospitalizations and caregivers with high levels of stress. Knowing the state of physical and mental health of the caregiver is of paramount importance in patient recovery and prevention of the consequences of burnout in the caregiver.

Keywords: Burnout; Informal Caregivers; Psychiatric Disorder; Non-Psychiatric Disorder.

RESUMO

Introdução: Burnout é uma síndrome psicológica caracterizada pela presença de exaustão emocional, atitudes de despersonalização ou cinismo e sentimentos de falta de realização pessoal. Esta presente principalmente em indivíduos que têm a tarefa ou responsabilidade profissional, social ou voluntária de lidar ou cuidar dos outros. **Objetivos:** Caracterização do Burnout e a identificação dos seus fatores de risco em uma população de Cuidadores Informais de Doentes com Transtorno Psiquiátrico (CIDTP) usando como controle os Cuidadores Informais de Doentes com Doença não Psiquiátrica (CIDDNP). **Materiais e Métodos:** A amostra de cuidadores informais consistiu em 80 indivíduos entrevistados no Hospital de Braga e na Casa de Saúde do Bom Jesus (Braga, Portugal); Metade eram CIDTP e metade CIDDNP. Para avaliar o Burnout, utilizou-se a versão geral do Inventário de Burnout de Maslach, e para a avaliação do estresse, estigma e estratégias de coping foram utilizadas as escalas PSS-10, AQ27 e CAMI, respetivamente. **Resultados:** Os CIDTP apresentaram níveis significativamente maiores de Burnout em comparação com os CIDDNP, sendo moderado nos CIDTP (média = 1,91, SD = 1,12) e baixo nos CIDDNP (média = 1,41, SD = 0,91). A percentagem de cuidadores com Burnout foi maior no grupo dos CIDTP (65%) comparado ao grupo dos CIDDNP (42%). O estresse teve um impacto significativo no modelo de regressão linear de Burnout no grupo dos CIDDNP em comparação com o grupo dos CIDTP. A eficácia das estratégias de coping teve mais impacto no Burnout dos CIDTP em comparação com os CIDDNP e o estigma da doença mental percebido pelos CIDTP não teve efeito em seus níveis de Burnout. O gênero feminino e o elevado número de readmissões do doente estiveram correlacionados com níveis altos de Burnout no grupo dos CIDDNP. O elevado grau de dependência do doente para as atividades instrumentais da vida diária, os pacientes mais jovens, a presença de doença crônica nos cuidadores ou o longo período como cuidador aumentaram significativamente os níveis de Burnout nos CIDTP em relação aos CIDDNP. **Conclusões:** É necessário fornecer aos cuidadores ferramentas necessárias para que possam lidar com as dificuldades da sua tarefa, particularmente cuidadores do sexo feminino, aqueles que têm uma doença crônica, aqueles cujos doentes têm elevado número de hospitalizações e cuidadores com altos níveis de estresse. Conhecer o estado de saúde física e mental do cuidador é muito importante para a recuperação do doente e na prevenção das consequências do Burnout no cuidador. **Palavras-chave:** Burnout; Cuidadores informais; Transtorno Psiquiátrico; Doença Não Psiquiátrica.

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LIST OF ABBREVIATIONS

- WHO** – World Health Organization
- IC/ICs** – Informal Caregivers
- FC** – Formal Caregivers
- PD** – Psychiatric Disorder
- NPD** – Non-Psychiatric Disorder
- PPD** – Patients with Psychiatric Disorder
- PNPD** – Patients with Non-Psychiatric Disorder
- ICPPD** – Informal Caregivers of Patient with Psychiatric Disorder
- ICPNPD** – Informal Caregivers of Patient with Non-Psychiatric Disorder
- CIDTP** – Cuidadores Informais de Doentes com Transtorno Psiquiátrico
- CIDDNP** – Cuidadores Informais de Doentes com Doença não Psiquiátrica
- ICPS** - Informal Caregivers of Patient with Schizophrenia
- ICPD** - Informal Caregivers of Patient with Depression
- SR** – Stress Response
- HB** – Hospital de Braga
- CSBJ** – Casa de Saúde do Bom Jesus
- MBI-GS** – Maslach Burnout Inventory-general version
- MBI-HSS** – Maslach Burnout Inventory-Human Service Survey
- MBI-ES** – Maslach Burnout Inventory-Educators Survey
- TB** – Total Burnout
- EE** – Emotional Exhaustion
- C** – Cynicism
- LPA** – Lack of Personal Accomplishment
- CAMI** – Carers Assessment of Managing Index
- DE/PS** - Dealing with Events/Problem Solving
- DS** – Dealing with Problems;
- AP** – Alternative Perception;
- PSS** – Perceived Stress Scale inventory
- AQ27** – Attribution Questionnaire 27

n – Number of the individuals in the sample
% - Percentage
SD – Standard Deviation
p – Significance Level
r – Pearson Correlation coefficient and Effect Size
r_s – Spearman Correlation Coefficient
r² or **R²** – Coefficient of Determination
α - Cronbach's Alpha
U – Mann–Whitney’s test score
H – Kruskal-Wallis test score
B – Coefficient of the predictors
SE – Standard error
β – Standardized **B**

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CHAPTER I

Introduction

1 INTRODUCTION

Burnout is a psychological syndrome characterized by the presence of strenuous exhaustion, feelings of cynicism, detachment from work, feeling of inefficiency and lack of personal accomplishment that results from prolonged exposure to stress in the workplace (Maslach, 2009). Although the term Burnout and its first description were made in 1974 by the American psychoanalyst Herbert Freudenberger in his book "*Stuff Burnout*," (Freudenberger, 1974) in fact this syndrome has always accompanied humanity in their work activities. For a long time, the stress in the work environment was attributed solely to personal matters, nothing to do with the company, and the employee might even be fired for being stressed at the workplace and producing less, there was no concern on the part of the employer (Maslach, 2009).

Currently Burnout is recognized as an occupational risk factor in professions that usually deal directly and continuously with people, especially with those who are suffering, so that some laws of some countries such as Brazil, consider burnout as an occupational disease in their laws (Fernando Henrique Cardoso, 1999) and Portugal in f) of Article 15 of Law 102/2009 of 10 September (Portugal, 2009) consider psychosocial factors relating to work in their labor laws as pathogenic agents of professionals diseases. Burnout affects not only the worker but also companies or firms due to increased sick leave, early retirement, job changes and dissatisfaction caused by this syndrome (Trigo, Chei, & Hallak, 2007). At the household and individual level, burnout increases the risk of addictive behavior, family and marital problems, cardiovascular problems and the consequent decline in the quality of life in the family (Fonte, 2011).

In 1998 the World Health Organization (WHO) considered the Burnout as a global problem, affecting all types of caregivers, from health professionals to the families who care for relatives suffering from chronic diseases, it can occur individually or collectively in caregivers (WHO, 1998).

In the patient treatment plan, there is more concern about the patient leaving aside the Informal Caregivers (family members, friends, and volunteers). This omission to assess the physical and mental health status of the Informal Caregiver (IC) in the patient's treatment process can have negative consequences on the recovery process and the readmission rate of the patient with chronic illness. The IC are the people who spend more time with their patients and with an unbreakable emotional connection with the patient even in their absence due to hospitalization, what does not happen as a rule in the Formal Caregivers (FC), although they feel a connection with the patients, at the time of patient discharge or professional shift exchange, this link may be broken. This analogy shows that IC who deal directly with chronic patients may be more exposed to stress factors comparing to FC.

This study was addressed to characterize the Burnout syndrome in IC of patients suffering from Psychiatric Disorder (PD) using as a control group the IC of patients with Non-Psychiatric Disorder (NPD). The specific objective was to understand the relationship between burnout and the following factors: Socio-demographic characteristics of the caregiver, caregivers stress, Psychiatric Disorder stigma perceived by the caregivers and the coping strategies adopted by the caregiver.

Commonly, the primary concern of health professionals is to take care of the patient, and there is no much concern about the health of IC, who have an important role in an efficient recovery of the patients. The results of this study can add more information to the discussion and understanding of Burnout in Families of Patients with Psychiatric Disorder in order to improve their quality of life and consequently of their patients.

Studies on factors that affect the number of days of hospitalization in acute care centers for Mental Illness, have demonstrated that health care alone did not reduce either the number of readmissions or days of hospitalization, community monitoring of the patient after discharge was shown to be essential for the patient recovery, which means that more must be done to the family members to reduce the numbers of readmissions (Zhang, Harvey, & Andrew, 2011).

CHAPTER II

Literature Review

2 LITERATURE REVIEW

2.1 Stress

The first description of stress linked to biology appeared in the journal *Nature*, in a brief article of the Hungarian Endocrinologist Hans Selye in 1936 as a completion of several experiments in mice in the same decade. In this article entitled "*Syndrome produced by diverse noxious agents*" Selye talks about the nonspecific adaptive response to maintain homeostasis in rats when exposed to stressors factors (Selye, 1936).

The maintenance of internal milieu constant as a condition for the continuation of life was earlier studied by the French Physiologist Claude Bernard around 1860. The name of Homeostasis to designate the maintaining constant internal milieu was established by American Physiologist and Physician Walter Cannon in 1929 and later comes the word stress, borrowed from physics by Han Selye first to name the factors that disrupt homeostasis and later to describe the response of the body against threats to homeostasis (Schneiderman, Ironson, & Siegel, 2005).

According to the American Psychological Association, Stress is the specific and nonspecific response to stimuli that exceed the body's ability to deal with adverse situations, in order to signal the homeostatic imbalance (Gerrig & Zimbardo, 2002).

The Stress Response (SR) begins with the activation of the Sympathetic Nervous System (SNS) and the Hypothalamic-Pituitary-Adrenal Axis, and according to Hans Selye, it takes place in three stages (Gonçalves, 2013; Selye, 1936), **Figure 1**. The first stage also called Alarm reaction warns the body of the presence of the stressor and it prepares the body to respond to the stimulus. This phase is characterized by the activation of the SNS within seconds, increasing the heart rate, the force of heart contraction and the blood pressure. The second stage is called Resistance Stage and it aims to mobilize all physiological, biochemical and psychological defenses of the body to fight against the stressor agent. The third stage is called Stage of Exhaustion, it occurs when the body doesn't have resources for coping and the body cannot overcome the stressor, leading to the appearance of disorders related to a poor adjustment to stressors like fatigue, anxiety, and depression (Gonçalves, 2013).

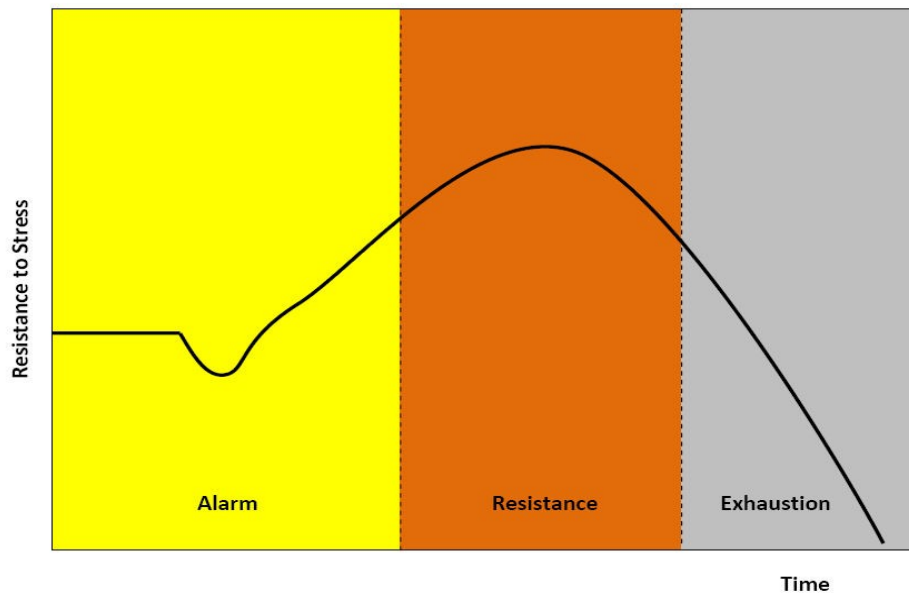


Figure 1: The three stages of Stress Response. (Wikipedia.org)

The SR can be acute or chronic. The Acute SR comes in the brief exposure to stressors factors and is characterized by changes in the nervous, endocrine, cardiovascular and immune systems in order to provide energy immediately and preferentially to the brain and muscles which will allow the body to get out of imminent danger. Chronic SR occurs when the acute response fails due to repeated activations by stressors factors, these reactivations lead to exaggerated responses, even to minor stressors. This response may have harmful consequences such as suppression of immunity, arterial hypertension, left ventricular hypertrophy, fatigue, malaise, and depression (Schneiderman et al., 2005).

The clinical manifestations of stress can be physical and mental. At the physical level, the individual with stress may present increased muscle tension, headache, migraine, hyperventilation, increased heart rate and contraction force, increased blood pressure, increased blood glucose, increased or decreased appetite, heartburn pain, gastric ulcer, diarrhea or constipation, erectile dysfunction or excitation in men, absence or irregularity of the menstrual cycle, and decreased sexual desire in women (APA, 2014).

At the mental level, the person may have emotional changes (characterized by irritability, anxiety, sadness, and exhaustion), cognitive changes (with amnesia, distractibility, increased concern and weak critical judgment) and behavioral changes particularly at sleep and wakefulness changes, increasing or

loss of appetite, drug use, neglect, isolation and suicidal behavior (APA, 2011; Shapiro, Shapiro, & Schwartz, 2000).

The Stressors factors can be of many kinds, from everyday events, personal events, traumatic and chronic events. Chronic stressors are those that bring repetitive and persistent psychological demands, highlighting the overwork, the caregivers of chronic patients, unemployment, divorce, war, abuse in childhood and many others (Schneiderman et al., 2005). Chronic stress factors are responsible for the appearance of Burnout.

2.1.1 Job Stress theories

There are several theories to explain the mechanism of the appearance of stress at work, but the most popular are the following: Lazarus's Transactional Model of Stress, Person-Environment Fit, Conservation of Resources Theory and the Job Demands–Control–Support Model (Dewe, O' Driscoll, & Cooper, 2012).

The Lazarus's Transactional Model of Stress was proposed by the physiologist Richard Lazarus in 1982, according to this theory, the appearance of stress depends on two types of the judgment of the threatening situation. The aim of the primary judgment is to identify whether the threat is relevant or not, and the second judgment has the objective to assess if are there resources to mitigate that threat. If there are resources to mitigate the stressor, the situation is taken as a challenge, leading to eustress. If there are no resources, the threat will take to sorrow and increasing concern that leads to stress (Dewe et al., 2012).

The Person-Environment Fit Theory arises in the 30s, according to it, the stress appears when the requirements needed to perform the work exceed the individual's abilities to perform the work. This theory for stress reduction proposes the necessity of congruence between the job requirements and the individual skills (demands–ability fit), as well as the fit between person's needs (physical, psychological and social) and the resources available to the person (needs–supplies fit). (Dewe et al., 2012).

Conservation of Resources Theory: This theory was proposed by Dr. Stevan Hobfoll in 1988. According to this theory people in their day to day act to acquire, maintain, protect and develop resources that allow them to cope with everyday adversities. Stress arises when there is the threat of losing those resources (such as the personal achievement, self-esteem, autonomy in the job, reward and others).

Psychosocial support is based on this theory since its purpose is to provide resources for coping (Dewe et al., 2012).

The Job Demands-Control-Support Model: This model was originally proposed by Karasek in 1979 and then revisited and improved by him and Theorell in 1990. This theory proposes that the control and the supervision in the workplace and the social support of Supervisors or colleagues is of particular importance for reducing the stress caused by the job demands. According to this theory, the stress level is influenced not only by the demand of stressors but also with the way of dealing with them, which means that each person has an individual response to the stressor according to his resources to deal with the demands (Dewe et al., 2012).

2.1.2 Work-related stress

The work has the both sides of the coin for the worker when we are talking about feelings, on one side as a source of pleasure and on the other as a source of suffering. It is presented as a source of pleasure when it provides to the worker, appreciation, admiration, respect, and recognition. These qualities that reinforce self-esteem can also be the source of suffering when the person does not reach them, which manifests itself in the form of fear, boredom, anxiety, and dissatisfaction. Stress at work comes in the last analysis when the worker has the perception that he and/or his work is not valued or recognized by those who are entitled or even by himself. (Martins, Ana Claudia Alves; Oliveira, 2006).

Work-related stress is a syndrome characterized by physiological, emotional, cognitive and behavioral reactions that arise when the worker's abilities to control demands at work are threatened. These threats can be the extreme work, poor organization and poor work environment in the workplace (Houtman & Jettinghoff, 2007).

The physiological response related to stress at work consists of increased heart rate, respiratory rate, blood pressure, and increased adrenaline and cortisol levels in the blood. In the behavioral changes, the worker can have an increase in making errors, impulsiveness, aggressiveness, increasing drug use, and an increased frequency of illness. In the emotional aspect, the worker can have fear, anxiety, an increase in irritability, nervousness and depression mood; and as cognitive alterations, he can have the forgetfulness and the reduction of attention and perception (Houtman & Jettinghoff, 2007).

2.1.3 Work-related stress model

The causes and the consequences of stress can be summarized in a model, as it can be seen below in **Figure 2**.

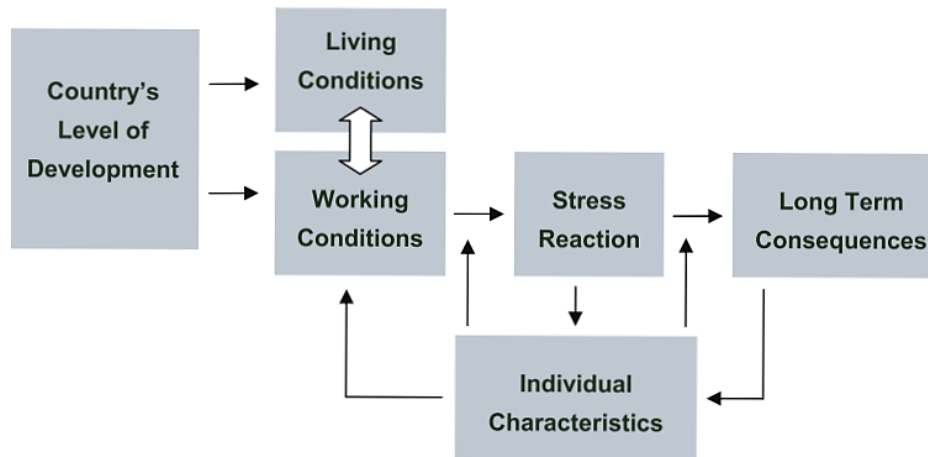


Figure 2: Model of Work-related stress (Houtman & Jettinghoff, 2007)

2.1.4 Causes of work-related stress

The causes of stress can be clustered into three groups: the causes related to the worker, those associated with the working conditions and causes related to the work-home interface. Within the characteristics of the employee, the most involved in the onset of stress is the degree of competitiveness, the extent of hostility, the degree of commitment and the level of confidence related to work. Other characteristics related to the worker are the age, gender, education level, personality, family situation, physical fitness, the ability to deal with problems, work's experience, the degree of optimism and the time that the individual support exposure to stress factors (Houtman & Jettinghoff, 2007).

Although the individual characteristics of the worker are important, many researchers have shown that working conditions appear to be the most stressful. The high rate of work, long periods of work, uncontrolled shifts, lack of control, low participation in decisions, lack of support from work colleagues and supervisors, insecurity at work, low pay, discrimination, and isolation appear as the most stressful factors (Houtman & Jettinghoff, 2007).

Work-related stress can result from non-reconciliation between work and home, especially for female workers, which can lead to family problems, divorce, and loss of work. The dilemma between the choice of household responsibilities and the profession has been a factor to be taken into account when we want to analyze the factors that cause stress in women. The choice within the family of those who will be responsible for sick or elderly family members is another factor that must be taken into account as well as the difficulties of day-to-day family logistics, domestic violence and the transformation of the home as a workplace (Houtman & Jettinghoff, 2007).

2.1.5 Work-related stress consequences

The effects of stress can be divided into short-term consequences and long-term consequences (Houtman & Jettinghoff, 2007).

The short-term effects of stress at work can be physiological, emotional, cognitive, and behavioral reactions. The physiological effects are the increased heart rate, increased respiratory rate, higher blood pressure, increased levels of adrenaline and cortisol, increased sweating and muscle tension. Emotionally, stress can lead to fear, irritation, depression, anxiety, anger and decreased motivation. As cognitive impairments the worker can have a reduction in attention, narrowing of perception, forgetfulness, problems of thinking, difficulty in solving problems and reduced learning ability. The Behavioral changes caused by stress are: reduction of productivity, increased drug use, increased errors at work and increased sick reports (Houtman & Jettinghoff, 2007).

Over the long term, chronic exposure to stress can lead to mental or organic illness as well as weakened immunity which in turn would increase the frequency of diseases and absenteeism in the worker. Some of the long-term consequences are Burnout and affective disorders, depression, hypertension, angina pectoris, metabolic diseases, alcoholism and musculoskeletal diseases (Houtman & Jettinghoff, 2007).

2.2 Burnout

2.2.1 Burnout concept

Service workers who are always dealing with clients with problems often difficult to solve, through a process of suffering transference from client to the employee, related to empathy, can experience frustration and feelings of anger, embarrassment, fear, despair and chronic stress, which in the long run may culminate with Burnout syndrome (Maslach, Jackson, & Leiter, 1996). The three keys factors that characterize Burnout are emotional exhaustion, cynicism feelings and lack of personal accomplishment (Maslach et al., 1996). Currently, the concept of Burnout is undergoing modifications, it is not just a phenomenon that affects professionals who are dealing with people daily, but a phenomenon that arises as a consequence of the relationship between the person and any type of work, even though the job has nothing to do with dealing with people directly (Chirkowska-Smolak & Kleka, 2012). Burnout comes as a means of measuring the degree of fit between the worker and the work he performs (Chirkowska-Smolak & Kleka, 2012). Many researchers, in addition to studying Burnout in professionals, already extend this study to family levels, between parents and children, and also between members of marriage (Maslach, 2009). Burnout can be defined as a syndrome that can be observed in professionals working with people or not, and it is characterized by the presence in its semiology, of emotional exhaustion, depersonalization or cynicism, and feelings of lack of personal accomplishment (Chirkowska-Smolak & Kleka, 2012).

The emotional exhaustion refers to the stress perceived by the worker, due to feelings of being overworked and lacking the emotional and physical resources to deal with these demands. The cynicism dimension of burnout has to do with the interaction between the worker and his work and is characterized by a lack of care, insensitivity, apathy and negative responses to various aspects of work. The professional begins to do what he can in his abilities leaving behind what he cannot, becoming this a vicious cycle that is characterized by the reduction of effective hours of work and empathy, which for the eyes of others is translated as inhuman attitude but is a mechanism of self-defense against emotional exhaustion due to overwork. Personal accomplishment refers to self-opinion about competencies, achievements, and productivity at work. The personal accomplishment is usually negative if the worker does not have the resources to carry out his work and if he has a lack of social support and few opportunities to develop in his profession, presenting low self-esteem, low morale, reduced productivity or capability, and an inability to cope with challenges (Maslach, 2009).

2.2.2 Theories of the burnout appearance

Within the several theories proposed to explain the appearance of Burnout in the worker, three ideas stand out: The Job strain model of Karasek and Theorell introduced in 1990, the Effort-Reward-Imbalance Theory proposed by Siegrist in 1996 and the Social Exchange Theory of Burnout proposed by Schaufeli in 1993 (Toppinen-Tanner, 2011). These three theories share a basic characteristic as a predictor of the appearance of Burnout, which is the degree of adjustment of the worker to his work environment as proposed in Edwards' 1996 Person-Environment Fit Theory (Toppinen-Tanner, 2011). According to this theory, the imbalance in the interaction between the worker and the demands of the work is the nuclear factor for the appearance of stress and later Burnout. There are 6 critical areas related to work, where the incompatibility between the worker and the work can lead to Burnout: the area related to workload, the degree of control at work, the degree of reward for the work performed, social support, ethical/moral values and the impartiality (Toppinen-Tanner, 2011).

The Job Strain Theory argues that the high workload combined with low supervision or lack of decision independence at work are responsible for the worker's stress and exhaustion in the workplace (Toppinen-Tanner, 2011).

The Effort-Reward-Imbalance Theory mentions that burnout appears when there is a perception on the part of the worker that their effort is not being valued or rewarded fairly (Toppinen-Tanner, 2011). The Social Exchange theory suggests that the work-related stress appears if there is a lack of reciprocity in the workplace when the worker has a feeling of having no return from the part of the other members of the team on his investments. Because of that he can experience stress and burnout that can be characterized by isolation, detachment, reduction in his degree of commitment to work, increased absences due to illness and greater intention to change or abandon work (Schaufeli, 2006).

2.2.3 Clinical manifestation of burnout

According to Maslach and Jackson, the main clinical signs of Burnout syndrome are emotional exhaustion, depersonalization or cynicism, lack of personal accomplishment and decreased professional efficiency. What is not known until now is the sequence of the appearance of these three symptoms in the development of this syndrome. Identification of the first symptoms is of paramount importance for early intervention and prevention of the development of severe forms of Burnout. Many theories about the

sequence of development of symptoms of burnout have been proposed as shown in **Figure 3**. For example, Maslach, Lee, Taris, and Leiter believe that the first symptom is emotional exhaustion, this, in turn, will lead to cynicism, which will result in decreased professional efficiency. According to Van Dierendonck, the first symptom is the lack of personal accomplishment which will lead to cynicism and this, in turn, leads to emotional exhaustion. Although many studies have shown insistently that emotional exhaustion is the first symptom to appear in the process of development of Burnout symptoms, it still remains how these three factors interact with each other in this process (Toppinen-Tanner, 2011)

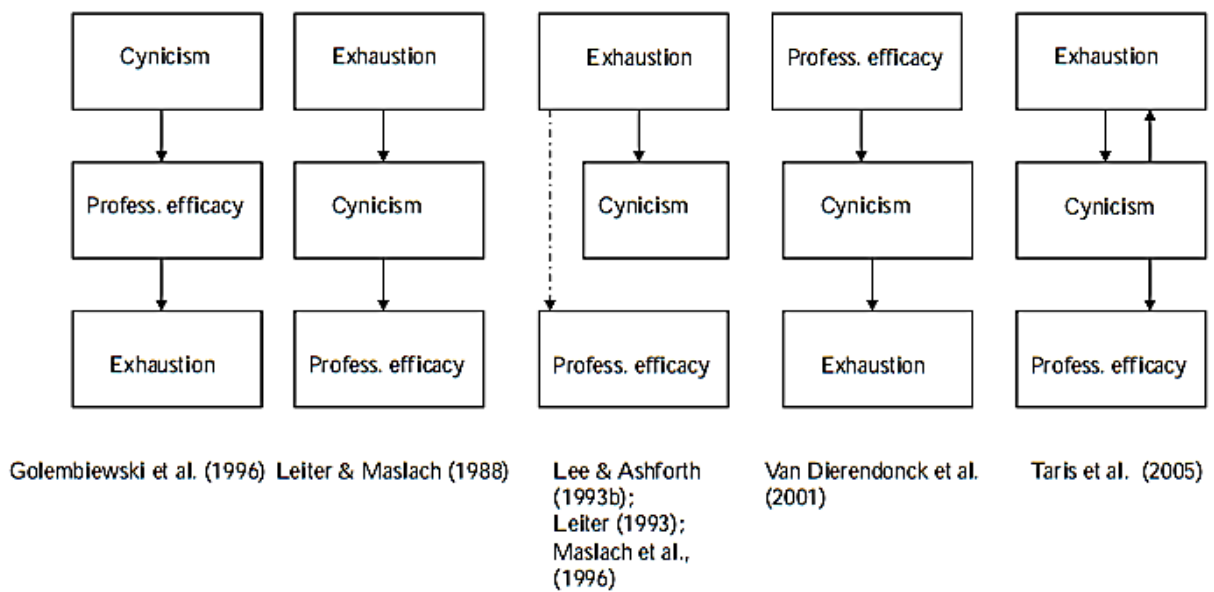


Figure 3. Different alternatives of sequential processes of development of burnout dimensions using the MBI-HSS or the MBI-GS (Toppinen-Tanner, 2011).

2.2.4 Burnout model

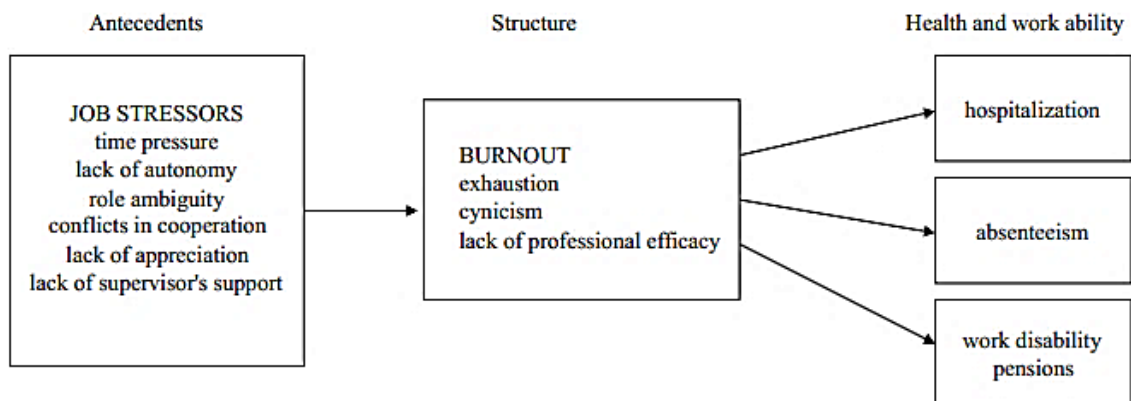


Figure 4. Model of Antecedents, structure, and consequences of burnout (Toppinen-Tanner, 2011)

The causes and the consequences of burnout can be summarized in a model, as it can be seen above in **Figure 4**.

2.2.5 Causes of burnout

According to Maslach the cause of Burnout can be personal and/or related to the characteristics of the work environment. Of these two, the causes related to the features of the work stand out as being the most important. There are six main risk factors related to the work environment, which can lead to the development of burnout when misfit: workload, control, reward, community, equity and values (Maslach, 2009).

Work overload - Work overload arises when there is a mismatch between the task and the time needed to perform the task or a mismatch between the demands of the job and the individual's ability to meet those job requirements. If this worker does not have the support of those who are entitled to adjust these tasks, he will be forced to sacrifice his leisure time and time for his family, leading to physical and emotional exhaustion.

Lack of control - The sense of lack of control of the tasks in which the person was held accountable can lead to a constant state of alertness, helplessness, and frustration that can lead to stress and burnout.

Insufficient reward - In addition to the material reward, many studies have shown that the mere recognition of work done by the worker has much significant impact on the quality of life and on the employee's spirit than material recognition. In the case of informal caregivers, patient improvement, collaboration, and appreciation of the caregiver of his work are the important factors in stress relief and burnout delay.

Lack of community - One way to prevent overloading in some members in the workplace is to have a sense of community among all members of the workforce, bosses, subordinates, and clients. The lack of a sense of community and mutual help among colleagues in the workplace can create a favorable environment for the development of stress and burnout. For informal caregivers, support among all family members is of extreme importance in reducing the burden on the primary caregiver and mitigation of Burnout.

The absence of impartiality - The impartiality refers to the consideration of all as equal. The perception of the absence of justice in the work environment can lead to cynicism on the part of the

workers. In a situation of lack of equity, the employee takes measures to restore equity; these actions are translated as hostile behaviors, violence, and abandonment of work.

Value Conflicts - Values are the ideals and goals that initially drew the person into their work. In addition to salary, values are the motivating connection between the worker and the workplace. Conflicts of value arise when people are working in a situation where there is a conflict between personal and organizational values. Prolonged exposure to value conflicts can lead to Burnout.

Many of the personal characteristics that can lead to the greatest risk of developing burnout are related to the personality of the individual. Some of these characteristics are: being a very competitive worker, being a hard worker, being someone with too much involvement, being pessimistic, being a perfectionist, being exaggerated optimistic, being a controlling person or being a passive person. The female gender is prone to a higher rate of emotional exhaustion, and the male gender is more prone to depersonalization. Individuals with higher education, single, widowed or divorced individuals also have an increased risk of developing burnout (Trigo et al., 2007).

Social factors outside work such as lack of family and social support, the maintenance of social prestige in a situation where the individual receives low wages and the cultural values and norms can precipitate the burnout syndrome (Trigo et al., 2007).

2.2.6 Burnout consequences

Burnout syndrome can have a negative impact on institutional, social, personal and work-related levels. At the individual level, burnout can increase the risk of hospitalization due to constant and progressive fatigue, musculoskeletal disorders, sleep disturbances, migraines, gastritis, gastric ulcers, constant colds, immunodeficiency, dermatological disorders from allergies, hair loss and white hair augmentation, cardiovascular diseases, respiratory diseases, sexual dysfunction and menstrual changes.

At the mental level burnout can cause lack of concentration, amnesia, slow thinking, emotional lability, discouragement, low self-esteem, feelings of guilt and impotence, loneliness, aggression, increased substance use and increased suicidal behavior (Trigo et al., 2007).

At the social level, burnout can lead to divorce and distance from other family members. It can also cause physical, emotional and financial harm to the people who depend on this individual, from family, work, and clients (Trigo et al., 2007).

Regarding quality of work, burnout has negative consequences that result in poor services, wrong procedures, negligence, and recklessness, physical and psychological abandonment of work. At the institutional level, burnout can cause time and money expenses due to constant staff rotations, absenteeism, and poor quality of work, dropouts and early retirement (Trigo et al., 2007).

2.3 Concept of Informal Caregivers

Approximately 27% of the European adult population will suffer from Psychiatric Disorder throughout their life (Vallejo, 2011). Although most Psychiatric Disorder do not interfere directly with the physical part of the patient however they can create some degree of mental incapacity to carry out their daily activities as well as to perform any work. Patients with mental disorders often need vigilance on the part of their relatives to not put themselves or others in dangerous situations. Whether in a health unit or at home, they will always need the support of someone, the caregiver.

According to the website www.cuidador.pt, "the caregiver is the person who assumes the function of assisting another person who, for typologically different reasons, has been affected by an incapacity of varying degrees that does not allow him to comply without help of another, all the acts necessary for its existence, as a human being ". When the caregiver is provided by public organizations or by profit and non-profit organizations, this caregiver is called the Formal caregiver, but when the caregiver comes from the family or community, it is known as the Informal caregiver. Informal caregivers usually have no remuneration and in addition to being carers may be employed, partially or full-time (Custódio, 2011; Santos, 2008).

The task of being informal caregiver usually starts insidiously without the caregiver himself noticing that he is taking responsibility for the patient or person. However, in other situations, it may happen suddenly, in cases of unexpected incidents such as after a major accident, illness, departure or death of the primary caregiver. The informal caregiver is usually a family member or someone very close to the patient as neighbors or friends when we are in the absence of the first (Custódio, 2011; Santos, 2008).

The features of the patient as well as the caregiver's characteristics may influence the family choice of the primary caregiver. Patient-related characteristics are age (the greater the patient's age, the greater is the caregiver's age), the patient's sex, and the degree of disability of the patient. The characteristics related to the caregiver are age, gender, marital status, relationship, residence,

employment, and motivations. Most caregivers are female between 45 and 60 years old and cohabit with the patient (Custódio, 2011).

The unemployed family members mostly are the most chosen and the other members may enter with other types of support such as the financial. The motivations for caregivers are usually of the cultural, religious, traditional or moral forum (Custódio, 2011).

2.4 Psychiatric Disorder

In the concept of health proposed by the WHO, mental health is also one of the most important parts to consider that the person is healthy. Mental health is not only the absence of Psychiatric disorder, but it is also the result of the interaction of biological, psychological and social factors (WHO, 2005).

Mental health is a state of well-being in which the individual is aware of his abilities, being able to cope with the normal stresses of life and to work productively and fruitfully to contribute to his community (WHO, 2005). Psychiatric disorder arises when this state is not reached, in the absence of physical or organic evidence to justify the mental disorder.

Psychiatric disorder is a syndrome characterized by clinically significant cognitive, emotional, or behavioral disorders that reflect psychological, biological, or developmental dysfunctions underlying mental functioning (APA, 2013).

Schizophrenic spectrum and Depressive disorders are the illnesses chosen to represent Psychiatric disorders in this study. The schizophrenia spectrum includes schizophrenia, schizotypal personality disorder, and other psychotic disorders. The main clinical manifestations of these disorders are delusions, hallucinations, disorganized thinking, disorganized or abnormal motor behavior, and negative symptoms like decreased emotional expression and avolition. Depressive disorders are characterized by the presence in the individual of sad, irritable or empty mood associated with cognitive and somatic changes that affect the functioning of the individual (APA, 2013).

The annual average of the incidence of schizophrenia in the world is 0.7%, of these patients one-third is asymptomatic, one-third has moderate symptoms, and one-third presents a severe impairment. The prevalence of depression within diseases, in general, is 10 to 20% but among Psychiatric disorders can reach up to 50% and only 10% of these patients is arriving at psychiatric clinics, leaving another 90% masked and lost in other specialties (Vallejo, 2011).

2.5 Psychiatric Disorder Stigma

The word stigma was created in ancient Greece to designate marks that were made with cuts or flames in slaves, criminals or traitors, as a way of highlighting the poor moral status of these people to promote their marginalization within society. This designation was also used in the Christian era to designate physical on the body signs supposedly originated by divine grace that had an erupting flower shape of the skin. For doctors, this designation was used to identify physical signs resulting from physical disturbances. At present, the term stigma refers primarily to the misfortune of having the defect rather than the physical evidence itself (Goffman, 1988).

For Goffman, society has the natural tendency to classify people as normal or imperfect according to norms or attributes that it establishes, whether socially, economically, culturally or politically, thus creating a virtual social identity in which people must mirror themselves to be or not part of the regular people. Stigma results from the discrepancy between the virtual social identity and the real social identity, this latter constituted by the real characteristics of the individual. Thus, the social stigma would be the physical or social mark with a negative connotation, which categorizes the individual in deteriorated and worthless in society, with consequent marginalization and social exclusion of this person (Goffman, 1988).

Goffman classified stigma in three types:

- Physical deformities including motor deficiencies, hearing deficiencies, visual defects, facial disfigurement, and other shortcomings;
- Behavioral deviations where we have mental disorders, addictions, drug addiction, sexuality deviations, prison imprisonment and others;
- Tribal stigmata related to race, nation, or religion.

The stigmatization attitude has as factors for its formation and maintenance the beliefs and prejudices that predispose the individual to certain behaviors or negative feelings about the stigmatized situation. These beliefs interfere with the process of object perception leading to a classificatory attitude or labeling attitude to other people. With the urbanization and modernization of societies, the public opinion through the sharing of information between individuals or groups and through the press has been proven to be a major vehicle in the formation, maintenance, and modification of beliefs and prejudices. The sharing of beliefs between groups and societies can lead to the transformation of individual beliefs into social attitudes leading to the generalization of stigmatization and the formation of social stereotypes or stigmas (Ronzani & Furtado, 2010).

Stigmatization may result in negative social consequences and even pathological implications for the personality of the stigmatized, resulting in coping strategies characterized by the tendency of escape from some situations that may become constraining to the stigmatized subject. This escape can have as consequences: social distancing, lack of access to health care, education, employment, housing and other (Ronzani & Furtado, 2010)

Although Psychiatric Disorder is not a physical problem, it is for patients an important source of suffering, with many repercussions, representing an obstacle to the realization of personal projects and a barrier to access to health care. It is also one of the causes of decreased self-esteem and self-concept (Xavier, Klut, Neto, Ponte, & Melo, 2013).

The stigmatization of Psychiatric disorder is something that has accompanied humans since antiquity, whose evidence is the clashes to explain its origin, religion defending a demonic origin and science (particularly Hippocrates) defending a medical conception. The other evidence is the conflicts between human treatments, championed by the church and Pinel, and punitive treatments, such as those advocated by Celsus. The community psychiatry movement defended the dismantling of asylums, promoting rehabilitation and social reintegration of patients, but this integration encountered a great challenge that was the prejudice and the stigmatization (Xavier et al., 2013)

Unfortunately, the person with Psychiatric disorder is still labeled with various stereotypes: as dangerous, unpredictable, responsible for his illness, lazy and victims worthy of pity. The adepts of these stereotypes are increasing for diseases like schizophrenia and are gradually shrinking to conditions such as depression and alcoholism (Xavier et al., 2013).

The stigmatization of the individual with Psychiatric Disorder can lead to problems of diagnosis and treatment. Studies have shown that these people are at higher risk of premature death due to under diagnosis and treatment related to stigma (Xavier et al., 2013).

The fight against stigma, whether in the family, in the community, in public or private institutions, and through governmental policies is of extreme importance not only to reduce discrimination but also to the recovery and social integration of the person living with Psychiatric Disorder because people transcend their illnesses (Xavier et al., 2013).

2.6 Concept of coping strategies

Newton's third law states that for every action there is always an opposite reaction of equal intensity. This principle also applies to interaction between man and the environment, when people are subjected to stress, there will always be a behavioral response to contain, manage or to counter stressors. This reaction consists of mechanisms of adaptation that can be conscious or unconscious, also called coping strategies. The failure of these mechanisms can give rise to great suffering on the part of those who are experiencing stress.

According to Lazarus and Folkman, coping strategies are a set of efforts, cognitive and behavioral, used by the individual to deal with specific internal or external demands that arise in situations of stress which exceed personal resources mobilized to face the Stressful situation (Richard S. Lazarus & Susan Folkman, 1984).

The coping strategies can be of two types: coping strategies focused on the emotion, and the coping strategies centered on the problem (Richard S. Lazarus & Susan Folkman, 1984). Coping strategies focused on emotion are the individual's efforts to regulate the emotional state or to reduce the unpleasant physical sensation associated with stress. Some of these strategies are smoking a cigarette, use of anxiety medication, watching television, going out for a run, and others (Antoniazzi, Dell'Aglio, & Bandeira, 1998).

The coping strategies focused on the problem are a set of efforts whose goal is to solve, eliminate, or modify the stressful situation. These coping strategies can be directed to internal or external problems. When addressed to internal problems, the coping strategies involve the cognitive restructuring and redefinition of the stressor. When directed to problems of external origin, the strategies consist of facing and resolving the problem or asking for help from others (Antoniazzi et al., 1998).

According to Stress and Coping Processing Model of Lazarus and Folkman (**Figure 5**), there is a ritual that the individual must follow when is facing a stressful situation and then evoke coping strategies. The ritual begins with the evaluation of the situation as threatening or non-threatening during the interaction between the individual and the environment, if it is evaluated as threatening, there will be a secondary evaluation about what efforts the individual needs to undertake or to manage the stressful situation and subsequent mobilization of those efforts or strategies. If the efforts that were taken have not yielded favorable results, the ritual will be restarted and can become a vicious cycle, increasing the levels of stress that can lead to Burnout.

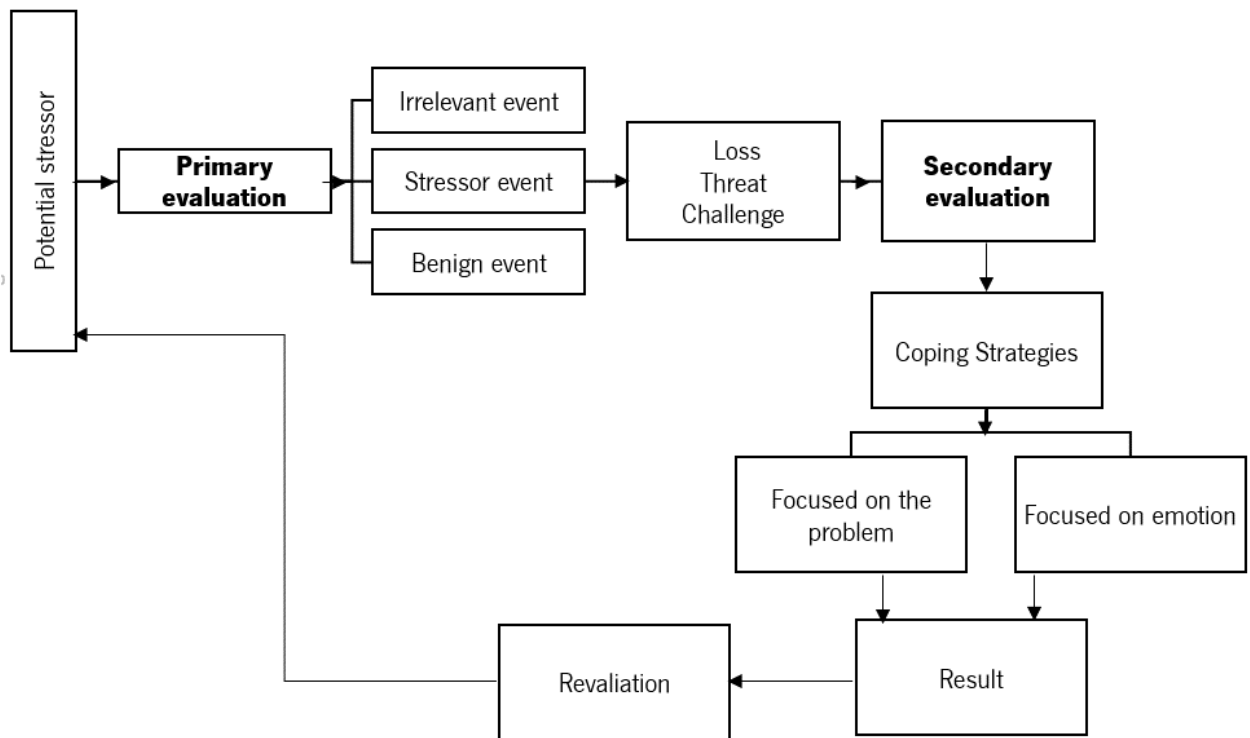


Figure 5. Stress and Coping Processing Model of Lazarus and Folkman (Antoniuzzi et al., 1998).

CHAPTER III

Objectives and Methodology

3 OBJECTIVES AND METHODOLOGY

3.1 Objectives

3.1.1 General objective

Starting from the hypothesis that informal caregivers of psychiatric patients have higher levels of burnout than informal caregivers of non-psychiatric patients, the overall aim is to characterize the burnout of Informal caregivers of patients with Psychiatric Disorder using as control the informal caregivers of patients with Non-Psychiatric Disorder.

3.1.2 Specific objectives

1. Characterize and explore Burnout differences between the different study groups of informal caregivers;
2. Characterize and explore the coping strategies, perceived stigma and stress differences among various groups of informal caregivers;
3. Investigate the relationship between burnout and stress, coping strategies, Psychiatric Disorder stigma and with socio-demographic data.

3.2 Hypothesis

1. Do the Informal Caregivers have different levels of stress and burnout compared to Formal Caregivers?
2. Will Informal caregivers of patients with Psychiatric Disorder have different levels of Burnout compared to Informal Caregivers of Patients with Non-Psychiatric Disorder?
3. Can the Burnout in Informal Caregivers be explained by the following factors: socio-demographic conditions, stress perceived by the caregiver, coping strategies and stigma related to Psychiatric Disorder?
4. Can the number of readmissions and hospitalizations be affected by burnout levels or vice-versa?

5. Is there a difference between the informal caregivers of patients with a psychiatric disorder and the informal caregivers of patients with non-psychiatric disorder in the perception of the stigma about Psychiatric Disorders?

3.3 Methodology

This study is a primary medical research, descriptive, cross-sectional and case-control (Röhrig, du Prel, Wachtlin, & Blettner, 2009). The sample was obtained through the convenience sampling technique.

3.3.1 Place of study and operationalization of data collection

The study was carried out in two Health Units, Hospital de Braga (HB) and “Casa de Saúde do Bom Jesus” (CSBJ) in Braga. The HB offers several health services including psychiatry services with outpatient and inpatient services with 41 beds, while CSBJ offers only inpatient psychiatric services including asylum services for female patients and has recently begun to receive some male patients.

The Informal caregivers of patients with Psychiatric disorder were selected from HB's psychiatry infirmaries (male and female ward) and CSBJ's São de Deus Unit. Informal caregivers of patients with Non-Psychiatric disorder (Chronic organic disease) were selected only from the HB internal medicine infirmary.

The choice of these hospitals was due to the ease of access and to one of the main objectives of the study, which is to compare Burnout among the informal caregivers of patients with a psychiatric disorder and the informal caregivers of patients with non-psychiatric disorders. This choice also enabled us to have the two genders of psychiatric patients.

In order to have access to the informal caregivers for the Study in these two hospitals, the letters of research request were sent to the HB and CSBJ ethics committees (**Annex – IX and Annex – X**), which were answered on day 19/09/2016 for CSBJ and on the day 12/12/2017 for the HB (**Annex – XI and Annex – XII**). The study was carried out between October of 2016 and May of 2017.

The Informal caregivers were approached during the visits to their relatives in the selected infirmaries for the research with the support of the nursing team and the doctors in service on that day.

The choice of family members to be interviewed depended on the inclusion and exclusion criteria to be part of the research.

The inclusion criteria of the informal caregivers in the study were: being over 18 years of age, being the caregiver of the patient for one or more years without payment, be the caregiver who spends more time with the patient when at home, be the caregiver who always visits the patient in inpatient services, his / her patient must have the study's target diagnosis for one or more years and must have at least one hospitalization.

The exclusion criteria were: to be less than 18 years old, to have a cognitive disorder defined as a score equal to or lower than 21 in the Mini-Mental State Examination and the refusal to sign or the withdrawing of the informed consent.

After determining the possibility of inclusion of the caregiver in the study, a brief presentation of the research project was made to the caregiver, explaining the objectives and the purposes of the investigation as well as the clarification of doubts, ensuring anonymity and free participation in the study. Subsequently, a copy of the participant's free and informed consent form (**Annex – I**) was delivered to read and sign if they agreed to participate in the study. Each caregiver who decided to take part in the study, filled in for one hour to an hour and a half, five surveys (**Annex – II to Annex – VIII**), namely: Socio-Demographic questionnaire, Maslach Burnout Inventory – General Version, Carers assessment of managing index (Coping Strategies Inventory), Attribution Questionnaire-27 and Perceived Stress Scale. The filling in was done on the edge of the patient or in the medical office according to the caregiver preference, after an explanation and guidance on filling them in.

3.3.2 Sample

The sample consisted of 80 informal caregivers. Half of the caregivers were Informal caregivers of patients with Psychiatric Disorder (ICPPD), and the remainder were Informal Caregivers of Patients with Non-Psychiatric Disorder (ICPNPD). About 12 caregivers were approached in CSBJ and 68 in HB. The sample size was determined by the convenience sampling criteria.

3.3.3 Data collection instruments

3.3.3.1 Socio-demographic inventory

The socio-demographic inventory (**Annex – II**) was composed of the personal information and the clinical information of the patients and caregivers. The personal information included in the inventory for both, patient and caregivers, were: age, gender, marital status, the degree of kinship, education, occupation, city or district where they live, home sharing with the patient, time spent daily caring for the patient and the period of time as a caregiver.

The clinical information of the patient included in the inventory were: Diagnosis, Number of readmission, days of hospitalization, and Smoking and alcoholic habits. For the caregiver, there were questions about psychiatric and psychological consultation, chronic diseases and about use of psychoactive drugs, cigarettes, and alcohol. The clinical information of the patient was obtained from the clinical files of the hospital, and the caregiver's clinical information was obtained through the interview.

3.3.3.2 Maslach burnout inventory

For assessment of caregivers burnout level, it was used the Maslach Burnout Inventory-General Survey (MBI-GS), produced by Shaufelli, Leiter, Maslach and Jackson in 1996, which was translated and validated into the Portuguese language (**Annex – V**) by Nunes in 1999 (Filipa Custódio Figueiredo Marques, 2011; Pires, Pio Abreu, & Oliveira, 2011; UNIESEP, 2011).

There are three types of versions of Maslach Burnout Inventories (MBI), the first type was invented in the 1970s by Maslach and Jackson whose name is Maslach Burnout Inventory-Human Service Survey (MBI-HSS), specific for Health and human services. The second type designed for workers in the education services called the Maslach Burnout Inventory-Educators Survey (MBI-ES), was invented in 1986 by the same authors and the third type that measures Burnout in any occupational context was invented in 1996 by Shaufelli, Leiter, Maslach, and Jackson and they gave the name Maslach Burnout Inventory-General Survey (MBI-GS) (Maslach et al., 1996; Maslach, Leiter, & Schaufeli, 2009; Toppinen-Tanner, 2011). All

three versions consist of three dimensions, the dimension of emotional exhaustion, the dimension of depersonalization or cynicism, and the dimension of efficiency at work (Maslach et al., 1996).

The choice of using the MBI-GS is due to its ability to measure burnout in any occupational context, which is in line with the purpose of the study, which is to measure Burnout in informal caregivers. This inventory is composed of 16 questions divided into three dimensions: Emotional Exhaustion, Cynicism, and Efficiency at work/personal accomplishment (Maslach et al., 1996).

The emotional exhaustion dimension consists of 5 questions, the first four questions in the inventory, and the 6th question (**Annex – V**). This dimension measures the degree of overstrain, tiredness or fatigue of the informal caregiver caused by the job of being a caregiver. The Cynicism dimension is composed of 4 questions, namely questions 8, 9, 14 and 15 of the MBI-GS and aims to measure the degree of indifference and lack of interest in the work of being a caregiver. The Personal Accomplishment (Efficiency in the work) dimension is composed of questions 5, 7, 10, 11, 12 and 16 of the MBI-GS and it aims to measure the degree of personal accomplishment (Toppinen-Tanner, 2011). The thirteenth question was omitted because of its ambiguity revealed in earlier studies (Marcelo da Silva Schuster, Dias, Grohmann, & Marquetto, 2013; Toppinen-Tanner, 2011).

The answers to questions of Emotional exhaustion and cynicism dimensions, are measured on a Likert scale ranging from zero to six, where zero (0) means “Never”, one (1) means a “Few times a year”, two (2) means “Once a month”, three (3) means “Sometimes a month”, four (4) means “Once a week”, five (5) means “Sometimes a week” and six (6) means Every day. The lack of Efficiency at work/personal accomplishment is measured on an inverse scale from Six (6) to Zero (0) in the questions of the dimension Efficiency at work, where six (6) means “Never”, five (5) means a “Few times a year”, four (4) means “Once a month”, three (3) means “Sometimes a month”, two (2) means “Once a week”, one (1) means “Sometimes a week” and zero (0) means Every day (Toppinen-Tanner, 2011). The participant usually takes 5 to 10 minutes to respond Survey (Maslach et al., 1996).

According to this scale, participants with Burnout will exhibit high levels of emotional exhaustion and cynicism but will exhibit low levels of work efficiency and high level of lack of personal accomplishment. The authors of the MBI-GS, implemented in 1996, did not recommend the calculation of the total Burnout score, classifying the individuals as having Burnout those who present high values in the Emotional Exhaustion and Cynicism dimensions, and small values in the Personal Accomplishment dimension (Toppinen-Tanner, 2011).

In 2006, Kalimo et al. implemented for the MBI-GS the calculation of the total burnout score for each participant according to the formula presented in **Table 1**, where the dimension of emotional exhaustion appears more heavily than the other two dimensions (Toppinen-Tanner, 2011).

$$\text{Burnout} = 0,4 * EE + 0,3 * C + 0,3 * \text{Lack of PA}$$

Table 1: The equation for calculation of the Total Burnout Score according to Kalimo et al. 2006 (Toppinen-Tanner, 2011). **EE** – Mean of Emotional exhaustion dimension, **C** – Mean of Cynicism dimension; **PA**– Mean of Personal Accomplishment dimension.

The MBI-GS also allows the classification of Burnout and their dimensions into levels, low, mild and severe according to the scale of **Table 2**. In the study was used calculation according to Kalimo et al. 2006.

Table 2. Classification of Total Burnout scores and its dimensions into low, mild, and severe burnout according to Kalimo et al. 2006 (Toppinen-Tanner, 2011).

Dimension	Low	Mild	Severe
Total burnout score	0 – 1,49	1.50 – 3,49	3,50 – 6
Emotional Exhaustion	0 – 1,49	1.50 – 3,49	3,50 – 6
Cynicism	0 – 1,49	1.50 – 3,49	3,50 – 6
Lack of Personal Accomplishment	0 – 1,49	1.50 – 3,49	3,50 – 6

3.3.3.3 Carers assessment of managing index

For the evaluation of the coping strategies used by the informal caregivers to face difficulties in their work, it was used the Carers Assessment of Managing Index (CAMI). Nolan et al. elaborated this

scale. in 1995(Nolan, Grant, & Keady, 1996) and later translated and validated to Portuguese (**Annex – VI**) by Brito and Sequeira (Sequeira, 2010; Soraya Coelho Gonçalves Machado, 2002).

CAMI aims to collect information about coping strategies used by care providers to deal with the difficulties perceived in their day-to-day tasks as informal caregivers, and it also allows to know if the strategies chosen had a result or not. If they give an effect, it allows knowing to what extent they are adjusted to the situation.

This index consists of 38 statements that are some of the coping strategies that care providers have used to face the difficulties in their daily lives(Nolan et al., 1996).

For each item, the respondent should indicate on a Likert scale with four options if the affirmation in question applies to their situation and if so, they should also indicate the perception of the efficiency of the procedure. On this scale the One (1) means "Do not proceed in this way," Two (2) - "Do not give results," Three (3) - Gives some result "and Four (4) -" It gives pretty good result "(Brito, 2000; Custódio, 2011).

The 38 CAMI's statements can be grouped into three categories: Dealing with events / Problem Solving, Dealing with stress symptoms and Alternative perceptions of the situation. The Dealing with events / Problem Solving category is composed by 14 statements (1, 3, 5, 10, 13, 14, 15, 17, 18, 23, 29, 30, 31, and 33). The category of Alternative perceptions about the situation is constituted by 15 statements (6, 7, 8, 9, 11, 12, 16, 20, 22, 24, 25, 26, 27, 32, and 34) and the Dealing with stress symptoms category is composed of 9 statements (2, 4, 19, 21, 28, 35, 36, 37 and 38) (Custódio, 2011).

The total CAMI score ranges from 38 to 152, a higher score indicates a greater use and an increased efficiency of coping strategies chosen. The participant "Does not use coping strategies" if the score is less than 76, if the score is between 76 and 114, it is considered "Perception of some effectiveness in the coping strategies used" and if it is greater than 114 it is Considered "High-efficiency perception in the coping strategies used" (Custódio, 2011). The central point of the score for the Dealing with events / Problem-Solving dimension is 35, for the dimension Dealing with stress symptoms is 22.5 and for Alternative perceptions of the situation is 37.5 (Soraya Coelho Gonçalves Machado, 2002).

3.3.3.4 Perceived stress scale

For evaluation of the perceived stress was used the Perceived Stress Scale inventory (PSS) created by Cohen in 1983 (Cohen, Kamarck, & Mermelstein, 1983) and translated and validated for

Portuguese population in 2009 (Ribeiro & T.Marques, 2009). The Portuguese version instead of 14 questions it is composed of 13 questions (**Annex – VIII**) because the question number 12 (“In the last month, how often have you found yourself thinking about things that you have to accomplish?”) of the original version shows very weak metric properties.

In this inventory, the respondents must choose within the five possible answers of the 13 questions, the alternative that most reflects his feelings. The five alternative answers for the questions can be "never"; "Almost never," "sometimes"; "Frequently"; and "Many times." Each response corresponds to a score. For questions 1, 2, 3, 8, 11, 12 and 13 "Never" is zero (0); "Almost Never" to 1 "Sometimes" to 2; "Very often" to 3; and "many times" to 4. For questions 4,5,6,7, 9 and 10 "never" corresponds to 4; "Almost Never" to 3 "Sometimes" to 2; "Very often" to 1; and "many times" to zero (0). The total score is the sum of all items for each participant. As the PSS inventory is not a diagnostic instrument, there are no cutoffs to classify in low, mild or severe stress, but is possible to make comparisons between people in the sample using quartiles(Tavolacci et al., 2013). The individual who has a higher sum of the scores of the 13 questions has high levels of stress (Ribeiro & T.Marques, 2009).

3.3.3.5 Attribution Questionnaire AQ-27

To assess the degree of stigma of IC towards people living with Psychiatric Disorder was used the Attribution Questionnaire 27 (AQ27) of Corrigan (P. Corrigan, 2008; P. W. Corrigan, Watson, Warpinski, & Gracia, 2004) in its Portuguese version validated in 2008 by Sousa et al. (Sousa, Marques, Rosário, & Queirós, 2012). This questionnaire (**Annex – VII**) consists of the presentation of a vignette about a hypothetical patient with Psychiatric Disorder, followed by 27 statements about how the participant would behave about this patient. For each statement, the participant should rank the degree of his agreement with the statement on a nine-point Likert scale, where one (1) means "nothing or no" and nine (9) means "very much or completely."

The 27 statements allow access to nine stereotypes through which the participants can classify the people living with Psychiatric Disorder: anger, dangerousness, fear, coercion, segregation, avoidance, help, pity and responsibility (P. Corrigan, 2008). Considering the AQ27 in **Annex – VII**, the Anger dimension was accessed through statements numbers 1, 4 and 12; The Dangerousness dimension through statements 2, 13 and 18; The Fear dimension by statements 3, 19 and 24; The dimension Coercion by statements 5, 14 and 25; The Segregation dimension for statements 6, 15 and 17; The

Avoidance dimension, statements 7, 16 and 26; The Help dimension by statements 8, 20 and 21; The Pity dimension by statements 9, 22 and 27; The Responsibility or Blame dimension for statements 10, 11 and 23 (Sousa et al., 2012).

The avoidance and the help dimension statements, unlike the statements of the other dimensions, are evaluated on a reverse Likert scale of 9 to 1 (P. Corrigan, 2008). The score of the AQ27 as well as its dimensions are calculated in the form of a mean and not as the sum of items, so the minimum score AQ27 is zero (0) and the maximum is nine (9) (Sousa et al., 2012)

3.3.3.6 Barthel index and Lawton index

For the evaluation of the patient's degree of dependence was used two instruments both translated by Sequeira in 2007, the Barthel Index (Barthel & Mahoney, 1965; Custódio, 2011) and Lawton index (Apostolo, 2012; Lawton & Brody, 1969).

The Barthel Index (**Annex – III**) assesses the ability to perform ten basic daily activities of daily living such as eating, bathing, dressing, taking care of their hygiene, ability to use the toilet, bowel and bladder control, ability to use the stairs and walking. Each activity has 2 to 4 levels of dependency, where the total dependence corresponds to zero (0) and the independence can correspond to 3 different degrees, 5, 10 or 15. The total score ranges from zero (0) to 100 points, smaller values show higher Degree of dependence. Values between 60-89 points show slight dependence; 40-55 Points correspond to moderate dependency; 20- 35 points show severe dependence and values less than 20 points show total dependency (Apostolo, 2012; Custódio, 2011).

Lawton's index (**Annex – IV**) assesses the ability to perform instrumental activities of daily living. It comprises eight tasks such as using the telephone, shopping, preparing food, cleaning the house, washing clothes, using transportation, preparing medication, and managing the money, by assigning a score according to the capacity of the subject evaluated to carry out these activities.

Each instrumental activity, according to Sequeira, may have 3 (1-3), 4 (1-4) or 5 (1-5) different levels of dependence. The total score of Lawton's index ranges from 8 to 30 points, where the higher score corresponds to the greater degree of dependence. Scores equal to 8 correspond to an independent individual, scores of 9 to 20 show moderate dependence and scores greater than 20 show severe dependence (Apostolo, 2012).

CHAPTER IV

Presentation and Analysis of Results

4.1 Descriptive Statistics

4.1.1 Statistical considerations

The data collected in the survey were initially introduced in the spreadsheet of the Microsoft Office Excel 2016 for Windows program, for quality control and subsequently, the results were processed and analyzed using the software Statistical Package for Social Sciences SPSS-21 for Windows, for a Confidence interval of 95%. The results obtained were considerate statistically significant in the cases which the p -value was less than 0.05.

The normality of all dependent variables (MBI-GS, AQ27, PSS, CAMI, Barthel Index and Lawton Index) for each category of independent variables was assessed using the Shapiro-Wilk's test (Razali & Wah, 2011), Skewness and Kurtosis tests, and through the visual evaluation of histograms, Normal Q-Q Plots and Box Plots. From this assessment of normality, most of the variables showed a non-normal distribution of the sample in some categories of the independent or Socio-demographic variables (**Appendix – I: Table 47** and **Appendix – II: Table 48**), which led us to choose non-parametric tests to evaluate the sample data.

For the descriptive statistics, was used the absolute frequencies, the maximum and minimum amplitudes, measures of central tendency (median and mean) and dispersion (standard deviation). For the comparison of the medians of two independent groups, the Mann-Whitney test was used, and for the comparison of more than two separated groups, we used the Kruskal-Wallis test. To quantify the correlation between two variables we used the Spearman correlation and to predict values of the dependent variables through the measurements of the predictor variables was used linear regression.

4.1.2 Sample characterization

4.1.2.1 Characterization of the general sample

The overall sample analyzed in this study was composed of 80 informal caregivers, of whom half were Informal caregivers of patients with Psychiatric Disorder (ICPPD) and the other half were Informal Caregivers of patients with Non-Psychiatric Disorder (ICPNPD). About 53 (66.3%) caregivers were female, and 27 (33.8%) were male, and the majority were married (**Table 3**).

Table 3: The absolute and relative frequency of Informal caregivers according to the categories of socio-demographic variables (Part 1).

Socio-demographic variables	Categories	n (%)
Hospital	CSBJ	12 (15.0%)
	HB	68 (85.0%)
Type of Informal Caregiver	ICPPD	40 (50.0%)
	ICPNPD	40 (50.0%)
Gender	Male	27 (33.8%)
	Female	53 (66.3%)
Marital Status	Single	20 (25.0%)
	Married	52 (65.0%)
	Divorced	4 (5.0%)
	Widower	4 (5.0%)
Education	4 ^o year	18 (22.3%)
	6 ^o year	9 (11.3%)
	9 ^o year	13 (16.3%)
	12 ^o year	17 (21.3%)
	Post-secondary education	6 (7.6%)
	High education	12 (15.0%)
	Master's degree	5 (6.3%)

CSBJ – Casa de Saúde do Bom Jesus; HB – Hospital de Braga; ICPPD – Informal Caregiver of Patient with Psychiatric Disorder; ICPNPD – Informal Caregiver of Patient with Non-Psychiatric Disorder.

Most of the caregivers interviewed lived in the District of Braga, and they were Employed Workers and the patient's children or patient ' s husband/wife (**Table 4**).

Table 4: The absolute and relative frequency of Informal caregivers according to the categories of socio-demographic variables (Part 2).

Socio-demographic variables	Categories	n (%)
Occupation	Unemployed	10 (12.5%)
	Employed Workers	33 (41.0%)
	Self-Employed	9 (11.3%)
	Retired	23 (28.8%)
	Retirement for disability	1 (1.3%)
	Student	3 (3.8%)
	Other	1 (1.3%)
Degree of Kinship	Husband/Wife	18 (22.5%)
	Father/Mother	8 (10.0%)
	Son/Daughter	33 (41.3%)
	Brother/Sister	7 (8.8%)
	Grandchildren	6 (7.5%)
	Nephew	3 (3.8%)
	Others	5 (6.3%)
District	Braga	58 (72.0%)
	Porto	6 (7.5%)
	Lisboa	2 (2.5%)
	Viana do Castelo	3 (3.8%)
	Others	4 (5.1%)

The overall mean age of participants was 49.8 years (SD = 15.9), women with the average age of 47.1 years (SD = 16.4) and men with 55.1 years (SD = 13.9). About one-fifth of the informal caregivers

interviewed were senior citizens, and only one-fifth were young adults between 18 and 34 years (**Figure 6**).

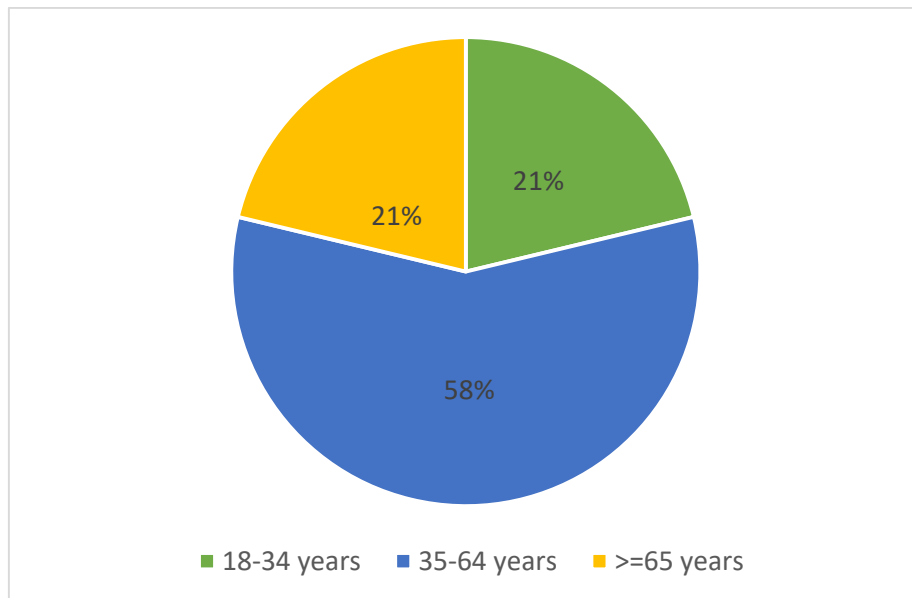


Figure 6: The relative frequency of Informal Caregivers by age groups.

Among the informal caregivers interviewed, 42.5% reported being caregivers for at least 1 to 2 years, and 35.0% of them were caregivers for more than a decade (**Figure 7**). Approximately 74.0% of the caregivers answered that during the year they took care of the patient daily (**Figure 8**) and 48.8% reported that they spent more than 5 hours a day caring for the patient (**Figure 9**). About 60.0% of the respondents shared the same residence with the patient, 92.5% cared for only one patient, 26.3% complained about not having the help of other family members, and 93.8% denied having the help of a social institution.

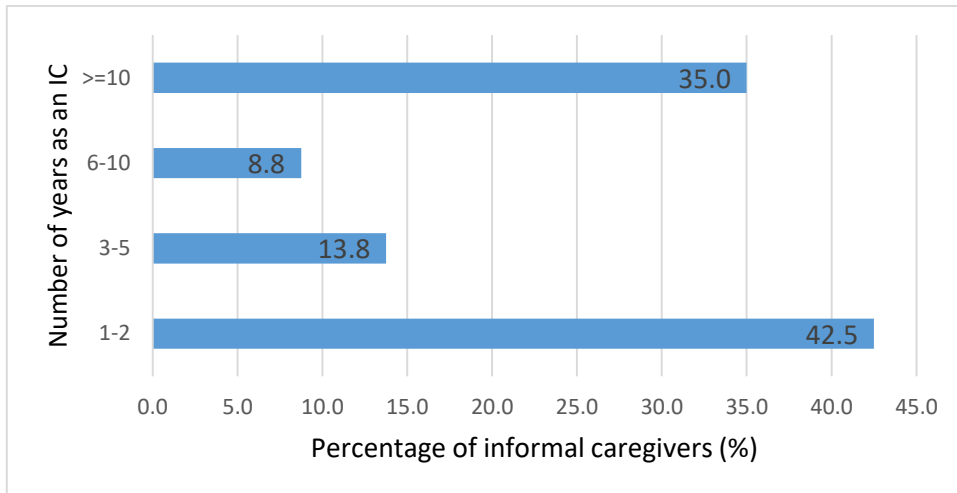


Figure 7: The relative frequency of IC according to the number of years as an IC. IC: Informal Caregivers.

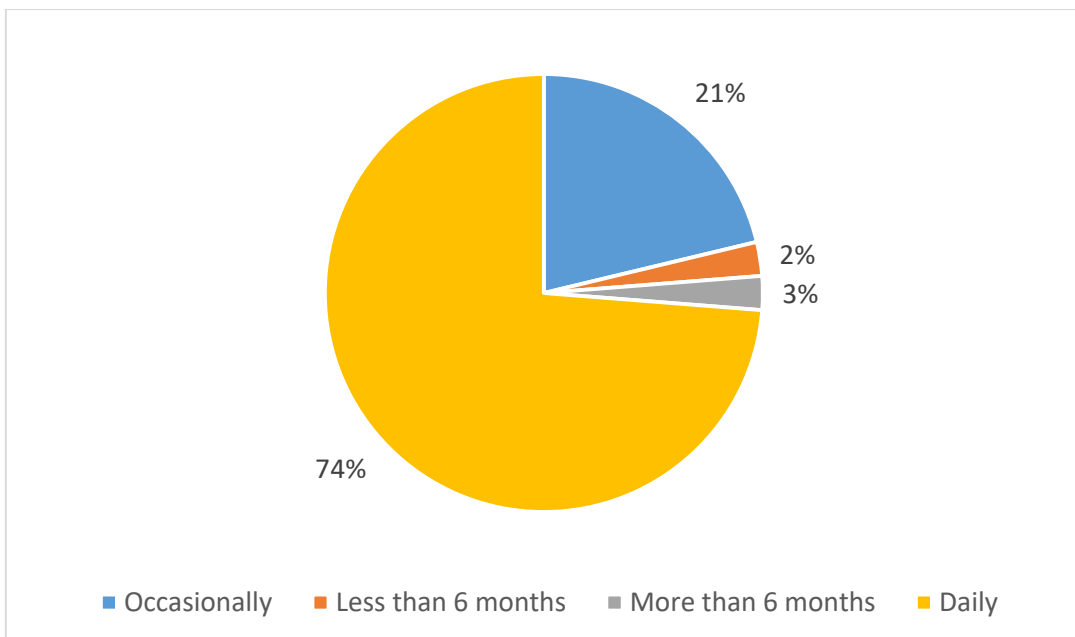


Figure 8: The relative frequency of Informal Caregivers according to the time spent annually caring for the patient.

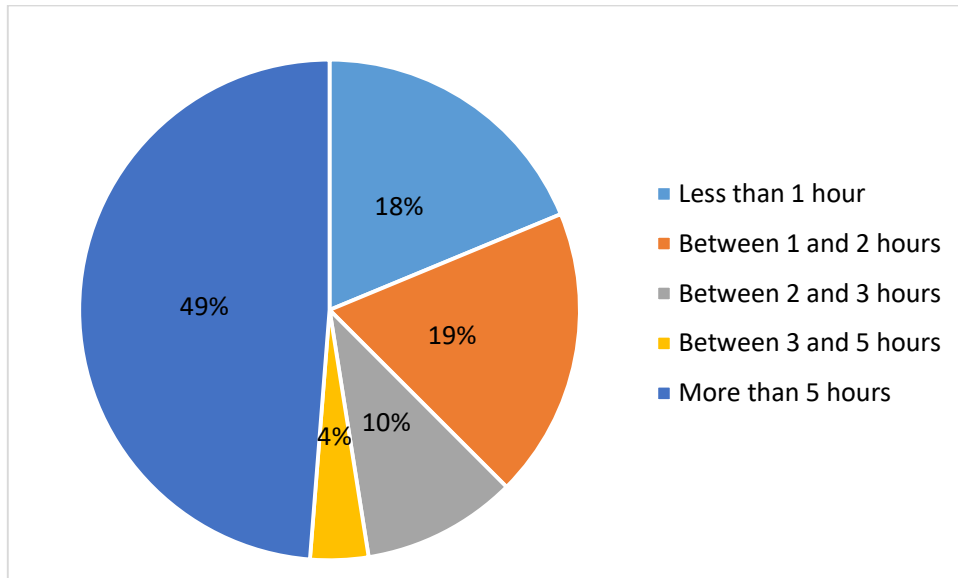


Figure 9: The relative frequency of Informal Caregivers according to the time spent daily caring the patient.

Regarding the looking for psychological or psychiatric help by caregivers, 13.8% reported that they had already sought psychiatric help and 11.3% had sought help from a psychologist. About 38.8% of the caregivers reported that they used in a recent past or were using psychoactive drugs, particularly the antidepressants drugs (**Table 5**).

Table 5: The absolute and relative frequency of Informal caregivers according to the categories of clinical variables.

Clinical variables	Categories	n (%)
Psychiatry consultation	No	69 (86.0%)
	Yes	11 (13.8%)
Psychology consultation	No	71 (88.8%)
	Yes	9 (11.3%)
Use of psychoactive drugs	No	53 (66.3%)
	Yes	27 (33.8%)
Kind of psychoactive drugs	BZD	9 (12.0%)
	ATD	12 (16.0%)
Smoker	No	68 (85.0%)
	Yes	12 (15.0%)
Number of cigarettes	< 5	3 (3.8%)
	5-9	4 (5.0%)
	10-14	3 (3.8%)
	15-24	1 (1.3%)
	>25	1 (1.3%)
Alcohol	No	48 (60.0%)
	Yes	32 (40.0%)
Frequency of alcohol consumption	Occasional	21 (26.3%)
	Daily	5 (6.3%)
	Others	6 (7.6%)

BZD – Benzodiazepines; ATD – Antidepressants

4.1.2.2 Characterization of the sample by groups of Informal Caregivers

4.1.2.2.1 Characterization of the group of Informal caregivers of patients with Psychiatric Disorder (ICPPD)

The group of ICPPD consisted of 40 participants, of whom 30.0% were caregivers of patients admitted to CSBJ (Casa de Saúde Bom Jesus) and 70.0% were caregivers of patients admitted to HB (Hospital de Braga). The minimum age was 22 years and the maximum age was 80 years (Mean = 49.3 years; SD = 15.8 years) and more than half of the participants were males (**Table 6**). The majority of ICPPD were self-employed and retired people (**Figure 10**).

Table 6: The absolute and relative frequency of Caregivers of Patients with Psychiatric Disorder according to the categories of the Socio-demographic variables.

Socio-demographic variables	Categories	n (%)
Hospital	Casa de Saúde Bom Jesus	12 (30.0%)
	Hospital de Braga	28 (70.0%)
Gender	Male	21 (52.5%)
	Female	19 (47.5%)
Age Group	18-34 years	10 (25.0%)
	35-64 Years	20 (50.0%)
	>= 65	10 (25.0%)
Marital Status	Single	10 (25.0%)
	Married	29 (72.5%)
	Widower	1 (2.5%)
Education	4 ^o year	7 (17.5%)
	6 ^o year	2 (5.0%)
	9 ^o year	7 (17.5%)
	12 ^o year	5 (12.5%)
	Post-secondary education	5 (12.5%)
	Bachelor degree	1 (2.5%)
	High education	12 (30.0%)
	Master's degree	1 (2.5%)

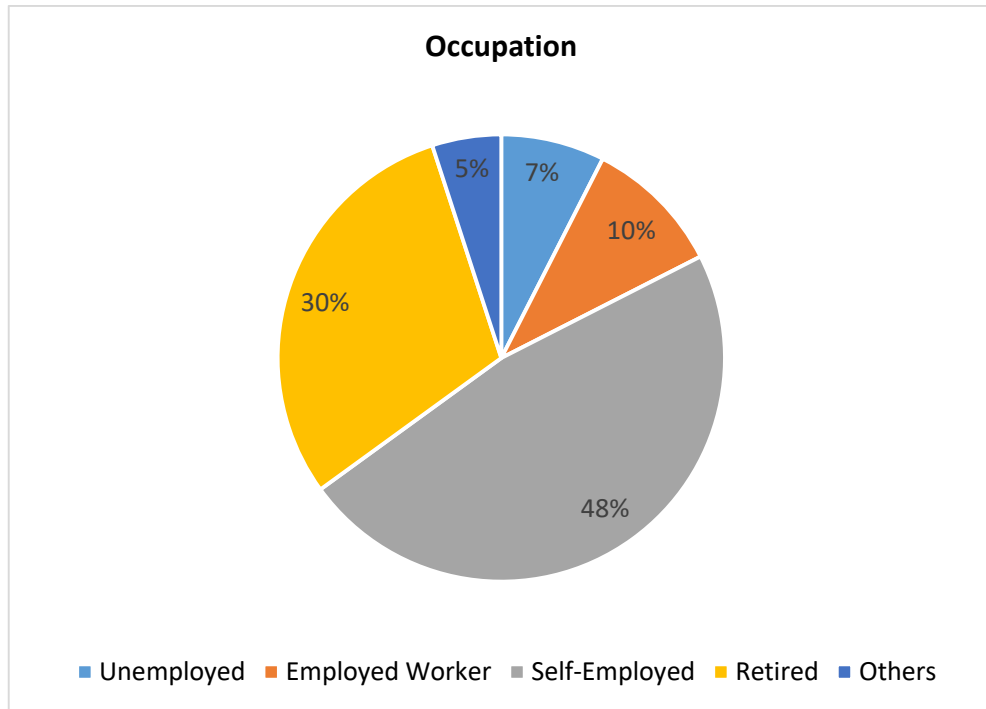


Figure 10: The Relative frequency of Informal caregivers of patients with Psychiatric Disorder according to the occupation.

Similar to the overall sample, most of the ICPPD interviewed were the patient's husband/wife or the patient's children. The majority of the ICPPD cared only for one patient and lived in the same residence with the patient. About 42.5% said that they had been taking care of the patient for more than ten years, 27.5% complained that they had no help from other family members, and 97.5% said that they had no help from any social institution. About three-quarters of ICPPD provided care for the patient every day, and 35.0% reported that they spent more than 5 hours a day caring for the patient (**Table 7**).

About 20.0% of ICPPD reported having already had a psychiatry consultation, 15.0% had already had at least one psychological consultation, and 40.0% had a chronic illness. Approximately 35.0% of the ICPPD used psychoactive drugs at some point since they began to take care of the patient, highlighting the antidepressants prescribed by the family doctor (**Figure 11**). About 20.0% were smokers, and 47.5% consumed alcohol, mainly occasionally.

Table 7: The absolute and relative frequency of Informal caregivers of patients with Psychiatric Disorder according to the categories of Socio-demographic variables.

Socio-demographic variables	Categories	n (%)
Degree of Kinship	Husband/Wife	12 (30.0%)
	Father/Mother	6 (15.0%)
	Son/Daughter	13 (32.5%)
	Brother/Sister	5 (12.5%)
	Others	4 (10.0%)
District	Braga	25 (71.4%)
	Others	15 (28.6%)
Home Sharing	No	16 (40.0%)
	Yes	24 (60.0%)
Number of patients under care	One	36 (90.0%)
	More than one	4 (10.0%)
Time spent annually caring the patient	Occasionally	8 (20.0%)
	Daily	30 (75.0%)
	Others	2 (5.0%)
Time spent daily caring the patient	Less than 1 hour	9 (22.5%)
	Between 1 and 2 hours	11 (27.5%)
	Between 2 and 3 hours	4 (10.0%)
	Between 3 and 5 hours	2 (5.0%)
	More than 5 hours	14 (35.0%)
Number of Years caring the patient	1-2 Years	14 (35.0%)
	3-5 Years	4 (10.0%)
	6-10 Years	5 (12.5%)
	More than 10 Years	17 (42.5%)
Family Help	No	11 (27.5%)
	Yes	29 (72.5%)
Institutional Help	No	39 (97.5%)
	Yes	1 (2.5%)

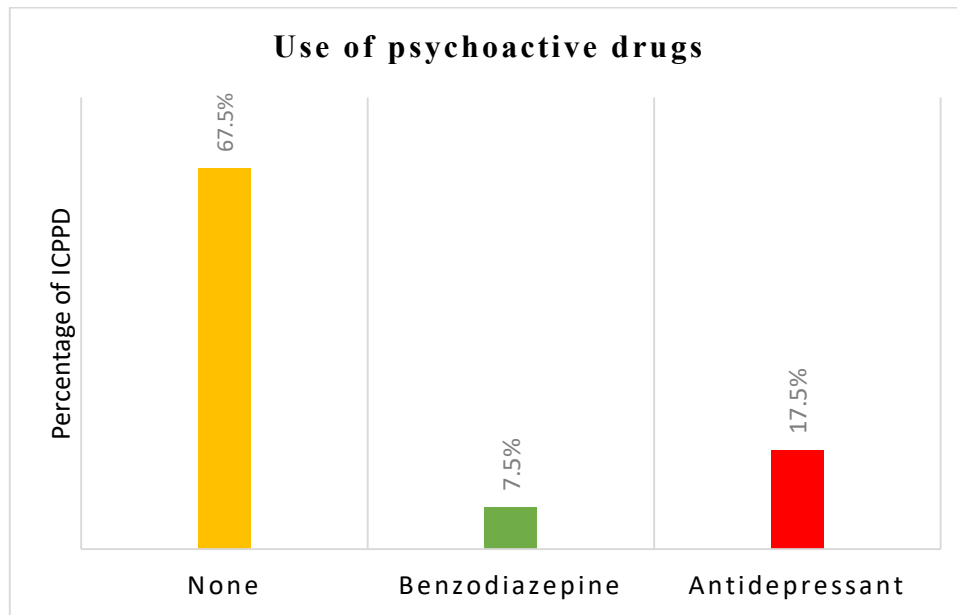


Figure 11: The relative frequency of ICPPD (Informal caregivers of patients with Psychiatric Disorder) according to the kind of psychoactive drugs they used.

4.1.2.2.2 Characterization of the group of Informal Caregivers of Patients with Non-Psychiatric Disorder (ICPNPD)

The ICPNPD group consisted of 40 participants, all of them were caregivers of patients admitted to HB. The minimum age was 18 years old, and the maximum age was 83 years old (Mean = 50.25 years; SD = 16.28 years), and most of the participants were female (**Table 8**).

Distinguishably to the overall sample, most of the ICPNPD interviewed were the patient's children. Most of the ICPNPD cared only for one patient and lived in the same residence with the patient. About 50% said that they had been taking care of the patient for one to two years, 25% complained that they had no help from other family members, and 90% said they had no help from any social institution. About 72.5% of ICPNPD provided care for the patient every day, and 62.5% reported that they spent more than 5 hours a day caring for the patient (**Table 9**).

Table 8: The absolute and relative frequency of Informal caregivers of patients with Non-Psychiatric Disorder according to the socio-demographic data.

Socio-demographic variables	Categories	n (%)
Gender	Female	34 (85%)
	Male	6 (15%)
Age Group	18-34 years	7 (17.5%)
	35-64 Years	26 (65%)
	>= 65	7 (17.5%)
District	Braga	33 (86%)
	Others	5 (13.1%)
Marital Status	Single	10 (25%)
	Married	13 (57.5%)
	Divorced	4 (10%)
	Widower	3 (7.5%)
Education	4 ^o year	11 (27.5%)
	6 ^o year	7 (17.5%)
	9 ^o year	6 (15%)
	12 ^o year	12 (30%)
	Post-secondary education	4 (10%)
Occupation	Unemployed	7 (17.5%)
	Employed Worker	5 (12.5%)
	Self-Employed	14 (35%)
	Retired	12 (30%)
	Others	2 (5%)

Table 9: Distribution of the absolute and relative frequency of the group of Informal caregivers of patients with Non-Psychiatric Disorder according to the socio-demographic data.

Socio-demographic variables	Categories	n (%)
Degree of Kinship	Husband/Wife	6 (15%)
	Father/Mother	2 (5%)
	Son/Daughter	20 (50%)
	Brother/Sister	2 (5%)
	Others	10 (25%)
Home Sharing	No	16 (40%)
	Yes	24 (60%)
Number of patients under care	One	38 (95%)
	More than one	2 (5%)
Time spent annually caring the patient	Occasionally	9 (22.5%)
	Daily	29 (72.5%)
	Others	2 (5%)
Time spent daily caring the patient	Less than 1 hour	6 (15%)
	Between 1 and 2 hours	4 (10%)
	Between 2 and 3 hours	4 (10%)
	Between 3 and 5 hours	1 (2.5%)
	More than 5 hours	25 (62.5%)
Number of Years caring the patient	1-2 Years	20 (50%)
	3-5 Years	7 (17.5%)
	6-10 Years	2 (5%)
	More than 10 Years	11 (27.5%)
Family Help	No	10 (25%)
	Yes	30 (75%)
Institutional Help	No	36 (90%)
	Yes	4 (10%)

About 7.5% of ICPNPD reported having already had a psychiatry consultation, 7.5% had already had at least one psychological consultation, and 20.0% had a chronic illness.

Approximately 32.5% of the ICPNPD used psychoactive drugs at some point since they began to take care of the patient, highlighting slightly the benzodiazepines prescribed by the family doctor (**Figure 12**). About 10% were smokers, and 32.5% consumed alcohol, mainly on the occasional form.

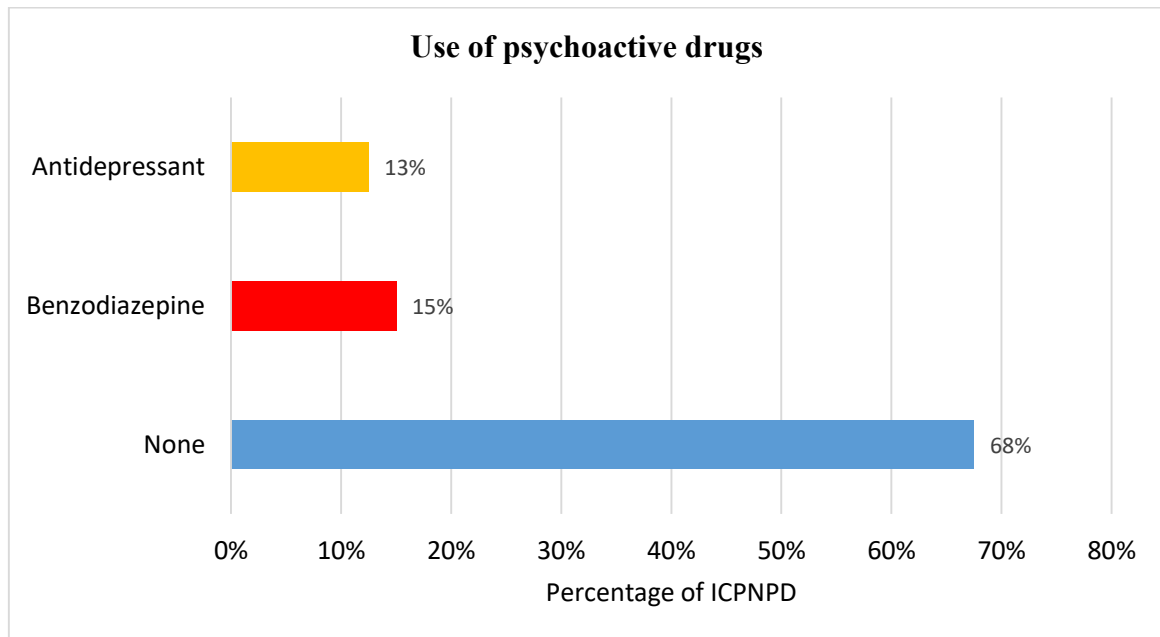


Figure 12: The relative frequency distribution of ICPNPD (Informal Caregivers of Patients with Chronic Organic Disorder) according to the kind of psychoactive drugs they used.

4.1.2.2.3 Characterization of the sample of Patients

The sample of patients consisted of 80 participants, half were Patients with Psychiatric Disorder (PPD), and the other half were Patients with Non-Psychiatric Disorder (PNPD). The majority of the PPD belonged to the middle age group between 35 and 64 years (mean = 55.4 years, SD = 1.8 years) and most PNPDs were elderly (mean = 77.1, SD = 2.7 years). The female gender stood out in both groups, PPD (80.0%) and PNPD (72.5%) (**Table 10**).

Table 10: The absolute and relative frequency distribution of patients according to the Socio-demographic variables.

Independent variables	Categories	n (%)	
		PPD	PNPD
Gender	Female	32 (80.0%)	29 (72.5%)
	Male	8 (20.0%)	11 (27.5%)
Age Group	18-34 years	3(7.5%)	2 (5.0%)
	35-64 Years	30 (75.0%)	4 (10.0%)
	>= 65	7 (17.5%)	35 (85.0%)
Marital Status	Single	9 (22.5%)	3 (7.5%)
	Married	21 (52.5%)	15 (37.5%)
	Divorced	6 (15.0%)	0
	Widower	4 (10.0%)	22 (55.0%)
Education	Illiterate	0	7 (17.5%)
	4 ^o year	16 (40.0%)	24 (60.0%)
	6 ^o year	7 (17.5%)	2 (5.0%)
	9 ^o year	5 (12.5%)	1 (2.5%)
	12 ^o year	7 (17.5%)	1 (2.5%)
	Post-secondary education	2 (5.0%)	3 (7.5%)
	High education	3 (7.5%)	2 (5.0%)
Occupation	Unemployed	3 (7.5%)	0
	Employed Worker	13 (32.5%)	2 (5.0%)
	Self-Employed	3 (7.5%)	1 (2.5%)
	Retired	11 (27.5%)	28 (70.0%)
	Invalid	6 (15.0%)	6 (15.0%)
	Others	4 (10.0%)	3 (7.5%)

PPD – Patient with Psychiatric Disorder; PNPD – Patient with Chronic Organic Disorder

The most frequent Psychiatric Disorder was the Depressive disorder with 62.5% among PPD (Figure 13), and the most prevalent organic disease was the Heart failure with 35.5% among PNPDs (Figure 14).

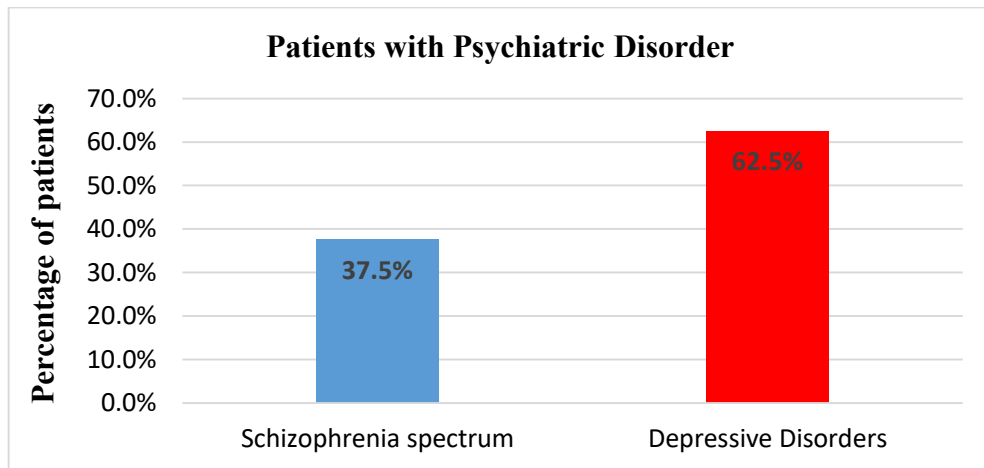


Figure 13: The relative frequency of Schizophrenia and Depression within the Patients with Psychiatric Disorder.

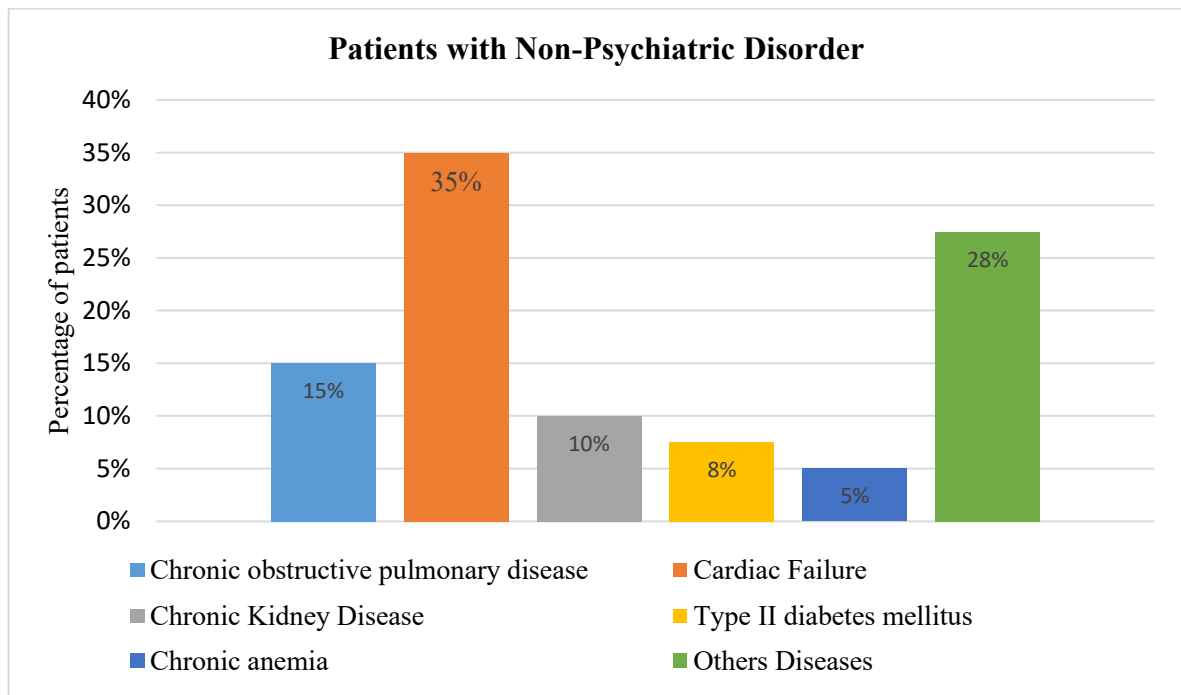


Figure 14: The relative frequency of chronic organic disorders within the Patients with the Non-Psychiatric Disorder.

The mean of the annual number of hospitalizations of PPD was 1.0 hospitalization/year (SD = 1.5) and for the PNPD was 0.5 hospitalization/year (SD = 0.6). The annual number of days of hospitalization ranged from zero to 224 days (Mean = 24.9 days; SD = 43.9 days) in PPD and for PNPDs ranged from 0.2 to 30 days (Mean = 4.8 days; SD = 5.5 days).

Regarding the degree of dependence of patients on activities of daily living, most of the PPDs were almost physically independent with a mean of Barthel Index of 97.4 (SD=8.1). At the other hand, the majority of the PNPDs were moderate to totally dependent, with an average of Barthel Index of 58.6 (SD=35.5) (**Figure 15**).

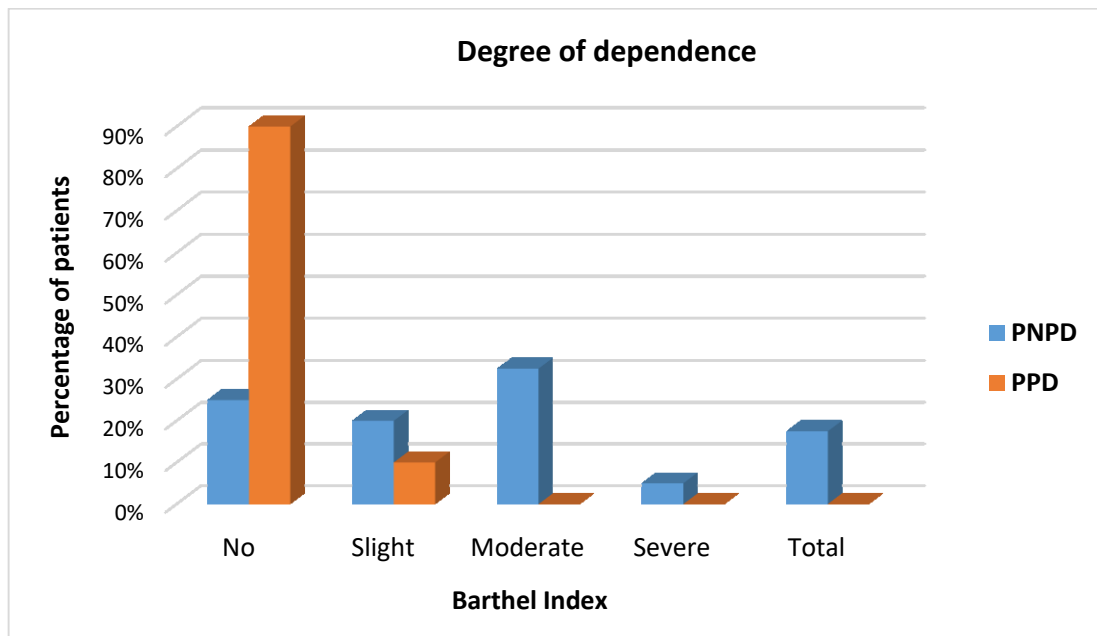


Figure 15: The relative frequency of PPD and PNPD according to the degree of dependence using the Barthel Index levels. PPD: Patient with Psychiatric Disorder; PNPD: Patient with Non-Psychiatric Disorder.

For instrumental activities of daily living, most of the PNPDs had a severe Lawton Index (Mean = 20.8; SD = 8.5), and the majority of the PPDs had a low to moderate Lawton Index (Mean = 13.5; SD = 8.5) (**Figure 16**).

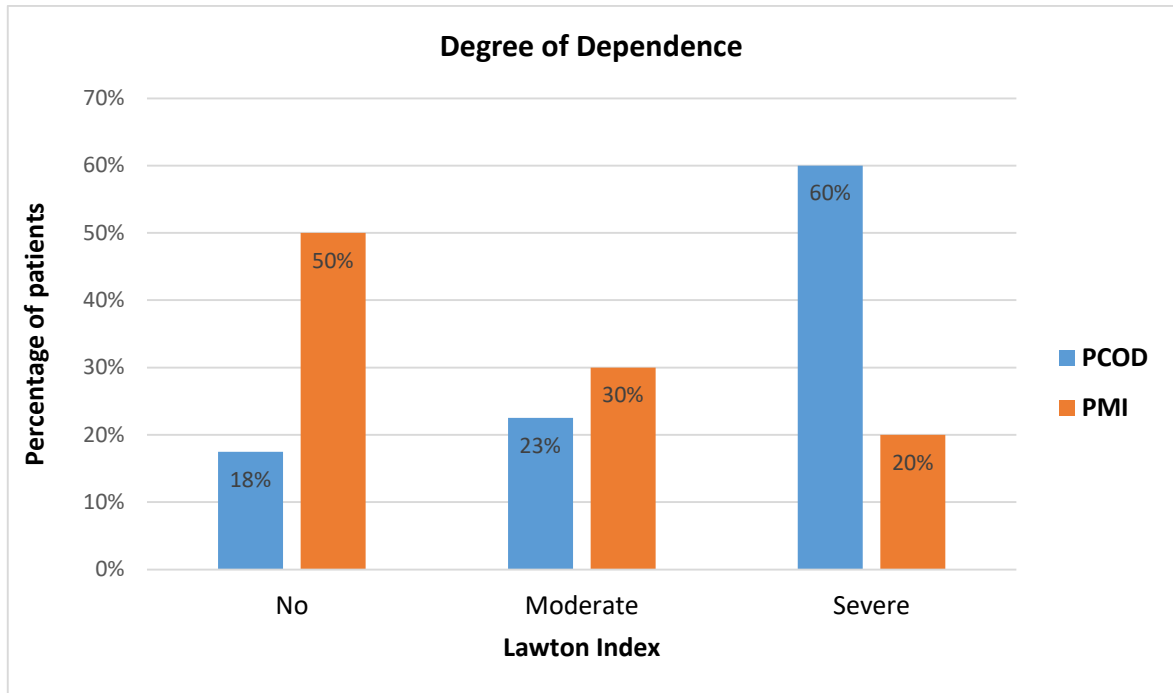


Figure 16: The relative frequency of PPD and PNPD according to the degree of dependence using the Lawton Index levels.

4.1.3 Descriptive analysis of the Maslach Burnout Inventory

The internal consistency of the MBI-GS was accessed by calculating the Cronbach's alpha, α (Andy Field, 2009), which showed a reasonable consistency of 0.76 when was included all the 16 items and showed a good consistency ($\alpha= 0.80$) when the item 13 was eliminated. The emotional exhaustion and lack of personal accomplishment dimensions both presented an excellent internal consistency ($\alpha= 0.87$), and the cynicism dimension exhibited a low internal consistency with a Cronbach's Alpha of 0.62 (**Table 11**). Similar values of Cronbach's Alpha were also found in several studies in Europe (Schutte, Toppinen, Kalimo, & Schaufeli, 2000).

The mean of the Total Burnout Score was 1.66 (SD = 1.04), 46% of the IC had low Burnout levels, and 45% had mild Burnout levels (**Figure 17**). For the three dimensions of Burnout, the emotional exhaustion dimension presented the highest average, and the cynicism dimension had the lowest mean (**Table 11**).

Table 11: Descriptive statistics and Cronbach's Alpha (α) of the Burnout scale and its dimensions.

Burnout Dimension	N	Minimum	Maximum	Mean	Std. Deviation	Cronbach's Alpha (α)
Emotional Exhaustion	80	0.00	6.00	2.65	1.79	0.87
Cynicism	80	0.00	5.75	0.96	1.16	0.62
Lack of Personal Accomplishment	80	0.00	5.50	1.03	1.42	0.87
Total Burnout	80	0.00	5.38	1.66	1.04	0.80

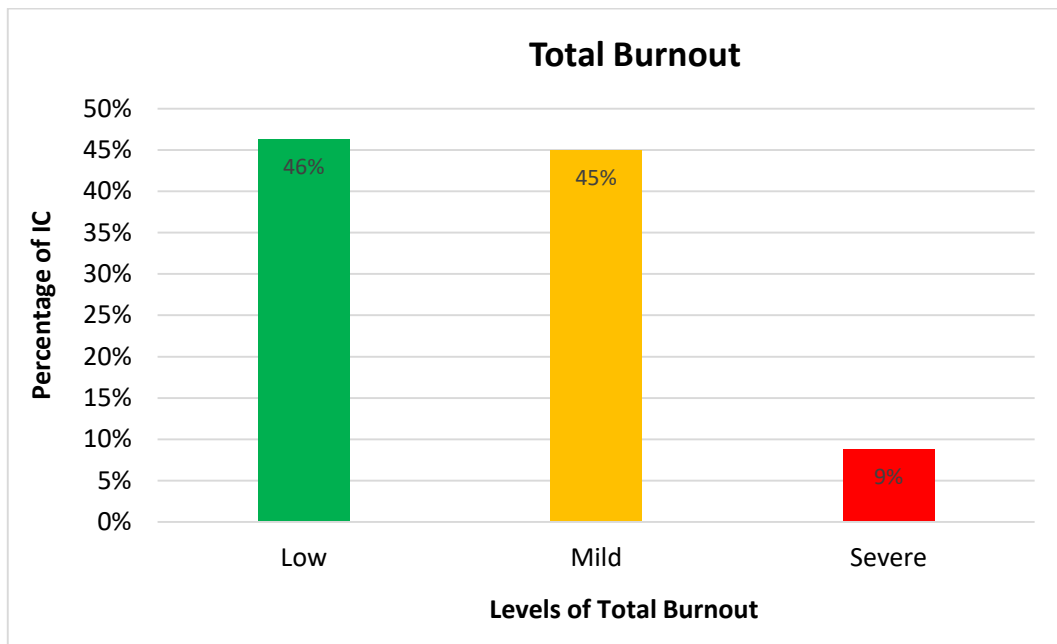


Figure 17: The relative frequency of Informal Caregivers according to the level of Total Burnout. IC: Informal Caregivers.

Concerning the burnout dimensions, about 33.8% of the IC presented a severe level of emotional exhaustion, 6.3% had a severe degree of cynicism, and 10% of the IC presented a severe lack of Personal accomplishment (**Table 12**).

Table 12: The absolute and relative frequency of the levels of emotional exhaustion, cynicism and personal accomplishment among the informal caregivers.

Level of Burnout	Emotional Exhaustion		Cynicism		Lack of personal accomplishment	
	n	%	n	%	n	%
Low	25	31.3	60	75.0	61	76.3
Mild	28	35.0	15	18.8	11	13.8
Severe	27	33.8	5	6.3	8	10.0

The mean of the Burnout score in the ICPPD was 1.91 (SD = 1.12) and 1.41 (SD = 0.91) in the ICPNPD. The relative and absolute frequencies of each level of Burnout and its dimensions are shown in **Table 13**.

Table 13: The absolute and relative frequency of the levels Total Burnout, emotional exhaustion, cynicism and personal accomplishment among the ICPPD and the ICPNPDs.

Type of Caregiver	Level of Burnout	Emotional Exhaustion		Cynicism		Lack of personal accomplishment		Total Burnout	
		n	%	n	%	n	%	n	%
ICPPD	Low	14	35	26	65	23	58	14	35
	Mild	13	33	11	28	10	25	21	53
	Severe	13	32	3	7	7	18	5	12
ICPNPD	Low	11	27	34	85	38	95	23	58
	Mild	15	28	4	10	1	3	15	37
	Severe	14	35	2	5	1	2	2	5

ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Psychiatric Disorder.

4.1.4 Descriptive analysis of the Coping Strategies

The Cronbach's Alpha of the global CAMI found in this study was the same as that found in a study of Elderly Caregivers in the city of Porto (Brito, 2000) which was 0.84. Among the categories of the CAMI, the category of Dealing with Events / Problem Solving had a highest Cronbach's alpha ($\alpha = 0.81$). The Dealing with Stress Symptoms and the Alternative Perceptions categories had lower internal consistencies, with the Cronbach's alpha of 0.63 and 0.64 respectively.

The CAMI score among the overall caregivers was between 67 and 140 (Mean = 109.8; SD = 15.0). About 39% of the Informal Caregivers had a high perception of the efficiency of the coping strategies they used, and 60% had a perception of some effectiveness (**Figure 18**).

On average, the ICPNPD (mean = 109.8, SD = 13.6), the ICPS (mean = 111.6, SD = 15.4) and the ICPD (mean= 108.7, = 17.0), all perceived some effectiveness in the coping strategies chosen to deal with the difficulties of the caregiver task translated by the mean being between 76 and 114.

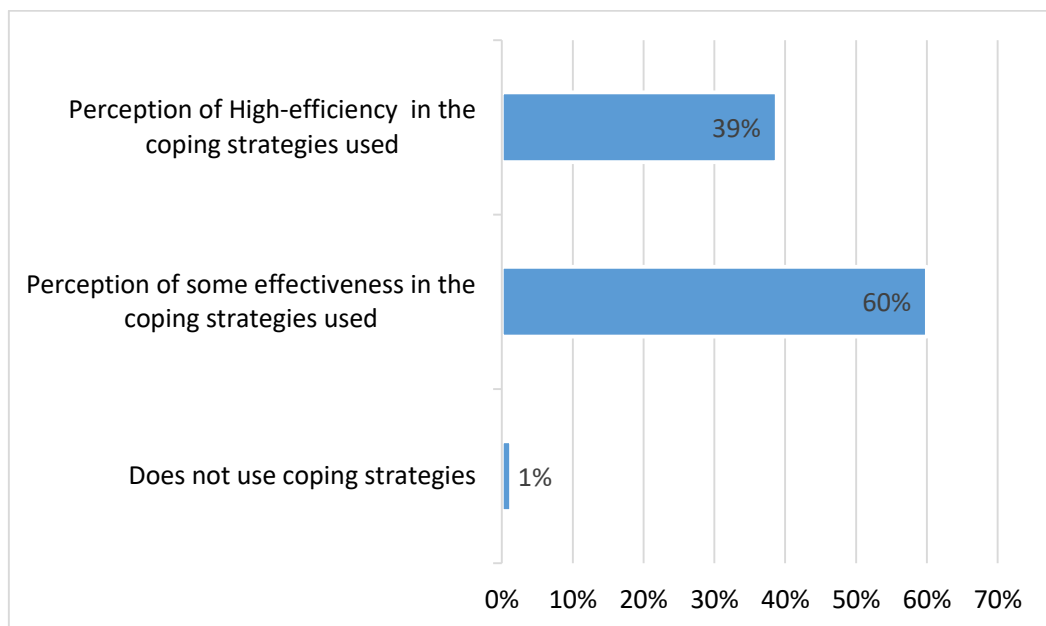


Figure 18: Relative frequency of informal caregivers according to the degree of perceived efficiency of the coping strategies.

The average score for each category of CAMI among the three types of caregivers was very similar, which means all the caregivers have a tendency to use the same types of coping strategies, regardless of

the patient's disease (**Table 14**). All the means of the CAMI dimensions were close to or above their central point values, which shows that informal caregivers regardless of the type of illness tend to cope well with the difficulties.

Table 14: Descriptive statistics of the CAMI and its categories in each group of Informal Caregivers.

Type of Caregiver	Descriptive Statistics	CAMI	DE/PS	DS	AP
ICPNPD	Mean	111.6	43.2	45.5	20.6
	Standard Deviation	15.4	7.2	5.7	5.0
	N	40	40	40	40
ICPS	Mean	109.8	44.9	44.5	22.2
	Standard Deviation	13.6	6.5	6.1	5.5
	N	15	15	15	15
ICPD	Mean	108.7	43.3	43.3	22.0
	Standard Deviation	17.3	9.1	6.3	4.9
	N	25	25	25	25

CAMI: Carers Assessment of Managing Index. DE/PS - Dealing with Events/Problem Solving; DS – Dealing with Problems; AP – Alternative Perception; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; ICPS - Informal Caregivers of Patient with Schizophrenia; ICPD - Informal Caregivers of Patient with Depression.

4.1.5 Descriptive analysis of the Perceived Stress Scale

In this study, the internal consistency (Cronbach's alpha) of the Perceived Stress Scale had a slightly lower value ($\alpha = 0.76$) than that found in the validation study of the scale which was 0.88 (Ribeiro & T.Marques, 2009).

The perceived stress score in the overall sample had extreme values of 4 to 44 (Mean = 25.6; SD: 6.9), and half of the informal caregivers had a PSS score of less than 25 (**Figure 19**).

The average of the Perceived Stress in ICPPD was 26.6 (SD = 5.6) and for ICPNPD was 24.5 (SD = 7.8). Among ICPPD, ICPS had a mean of 27.0 (SD = 6.4), and ICPD had an average of 26.3 (SD = 5.6).

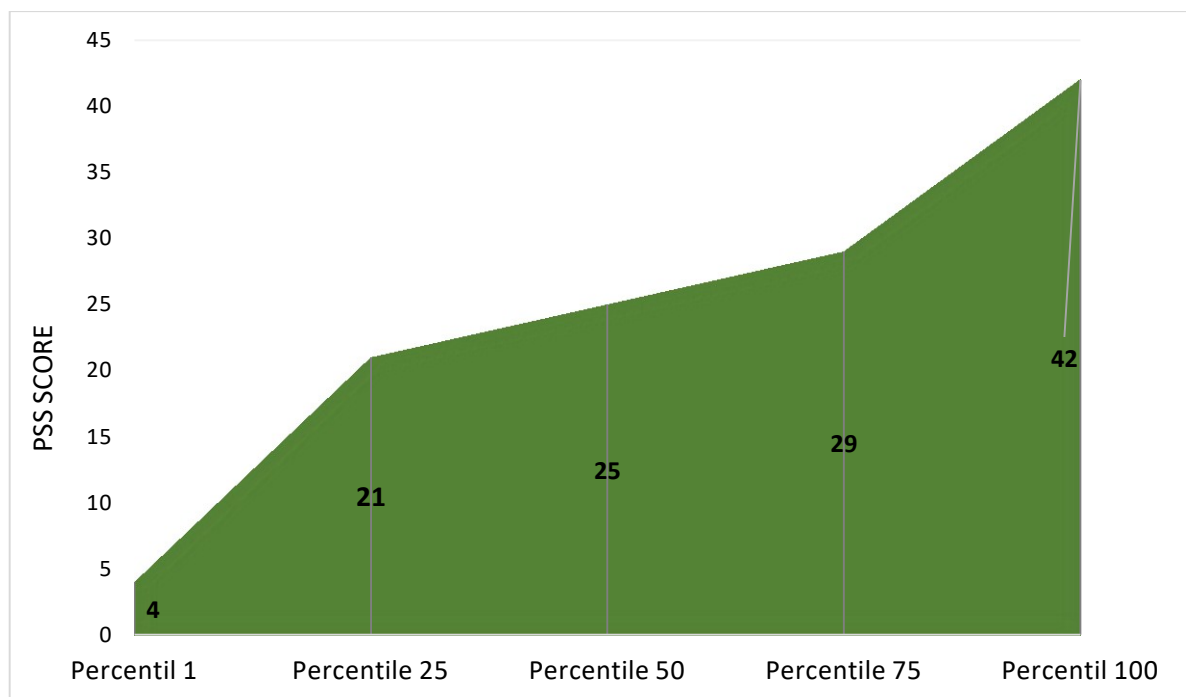


Figure 19: Distribution of the PSS score according to the percentiles of the overall sample. PSS: Perceived Stress Scale.

4.1.6 Descriptive analysis of the Attribution Questionnaire 27 inventory (AQ27)

The AQ27 inventory for stigma assessment had a good internal consistency with Cronbach's alpha of 0.81 as the others studies carried out for the Portuguese population (Sousa et al., 2012). From the nine dimensions of the AQ27 the Anger, Dangerousness and Fear dimensions presented a good internal consistency of the items, the dimensions Segregation, Avoidance, Help, and Pity showed a reasonable Internal Consistency and the Coercion and Responsibility dimensions presented very low Cronbach's alpha (**Table 15**).

Table 15: Descriptive statistics and Cronbach's Alpha of the different dimension of the Attribution Questionnaire 27 (AQ27) in the general sample.

AQ27 Dimensions	N	Minimum	Maximum	Mean	Std. Deviation	Cronbach's Alpha (α)
Anger	80	1.0	7.3	1.8	1.3	0.72
Dangerousness	80	1.0	8.7	1.9	1.4	0.85
Fear	80	1.0	9.0	1.8	1.5	0.90
Coercion	80	1.3	9.0	5.9	1.6	0.42
Segregation	80	1.0	8.0	2.6	1.8	0.62
Avoidance	80	1.0	8.7	3.3	2.1	0.68
Help	80	1.0	7.7	2.7	1.6	0.63
Pity	80	1.0	9.0	5.3	2.1	0.69
Responsibility	80	1.0	9.0	3.3	1.3	0.28
Level of Psychiatric Disorder Stigma	80	1.8	5.7	3.2	0.9	0.81

On a scale of 1 to 9, the degree of stigmatization of the patients with Psychiatric Disorder by informal caregivers had a small mean of 3.2 (SD = 0.9). The dimensions Coercion, Pity, Responsibility and Avoidance had a greater contribution to this stigmatization (**Figure 20**).

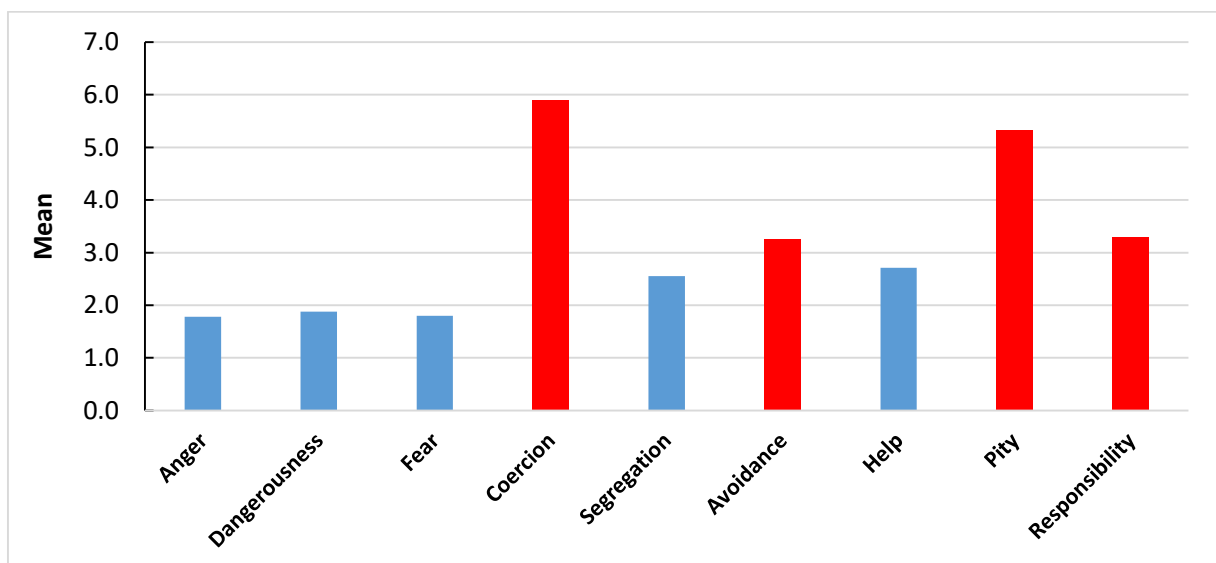


Figure 20: The mean score of each dimension of Attribution Questionnaire 27 in the overall sample. In red the stereotypes that gave more contribute to the total perceived stigma score.

The Total stigma scores were similar between the ICPPD and the ICPNPD. Among the ICPPD, the stigma stereotypes that had elevated score were the Coercion and Pity, followed by Responsibility, Help, and Avoidance (**Table 16**).

Table 16: Descriptive statistics of the different dimension of stigma using the Attribution Questionnaire 27 (AQ27) in the Informal Caregivers of Patient with Psychiatric Disorder (ICPPD).

AQ27 Dimensions	N	Minimum	Maximum	Mean	SD
Anger	40	1.0	7.3	2.0	1.3
Dangerousness	40	1.0	8.7	1.9	1.5
Fear	40	1.0	9.0	1.8	1.4
Coercion	40	2.0	8.7	6.0	1.2
Segregation	40	1.0	7.3	2.6	1.7
Avoidance	40	1.0	6.77	3.0	1.7
Help	40	1.0	7.7	3.1	1.5
Pity	40	1.3	9.0	4.9	1.8
Responsibility	40	1.7	9.0	3.4	1.3
Level of Psychiatric Disorder Stigma	40	1.9	5.7	3.2	0.8

AQ27 - Attribution Questionnaire 27; SD – Standard Deviation

For the ICPNPD, Coercion and Pity were also highlighted first, followed by Avoidance, and Responsibility (**Table 17**).

Table 17: Descriptive statistics of the different dimension of stigma using the Attribution Questionnaire 27 (AQ27), in the Informal Caregivers of Patient with Non-Psychiatric Disorder (ICPNPD).

AQ27 Dimensions	N	Minimum	Maximum	Mean	SD
Anger	40	1.0	6.3	1.6	1.2
Dangerousness	40	1.0	5.3	1.8	1.4
Fear	40	1.0	7.7	1.8	1.6
Coercion	40	1.3	9.0	5.8	1.8
Segregation	40	1.0	8.0	2.5	1.9
Avoidance	40	1.0	8.7	3.5	2.4
Help	40	1.0	7.7	2.3	1.7
Pity	40	1.0	9.0	5.8	2.3
Responsibility	40	1.0	6.3	3.2	1.2
Level of Psychiatric Disorder Stigma	40	1.8	5.6	3.1	1.0

AQ27 - Attribution Questionnaire 27; SD – Standard Deviation

4.2 Inferential Statistics

4.2.1 Comparative analysis of the medians

4.2.1.1 Burnout

4.2.1.1.1 Burnout and the Type of Caregiver

Taking into account the overall sample, the Burnout level of the ICPPD (Median = 1.74) was significantly different (Mann–Whitney $U = 561.5$, $p < 0.05$) from the level of Burnout of the ICPNPD (Median = 1.22). However, the Effect Size was small ($r = -0.26$) and the Coefficient of determination ($r^2 = 0.068$), showed that only 6.8% of the Burnout variance was explained by the Type of Caregiver (**Figure 21.A**).

Within the ICPPD, there was no statistically significant difference in the levels of Burnout ($U = 152$, $p > 0.05$, $r = 0.16$) between Caregivers of Patients with Depressive Disorder (median = 1.62) and Caregivers of Patients with Schizophrenia (median = 2.12) (**Figure 21.B**).

In the comparison of Burnout levels between the ICPNPD (median = 1.22) and the Informal Caregivers of Patients with Schizophrenic Spectrum (median = 2.13) was found statistically significant difference ($U = 193.0$, $p < 0.05$), but the Effect Size was small, $r = -0.27$ (**Figure 21.D**).

Between the ICPNPD and the Informal Caregivers of Depressed Patients, there were no statistically significant differences in the level of Burnout, $U = 368.5$, $p > 0.05$, $r = -0.22$ (**Figure 21.C**).

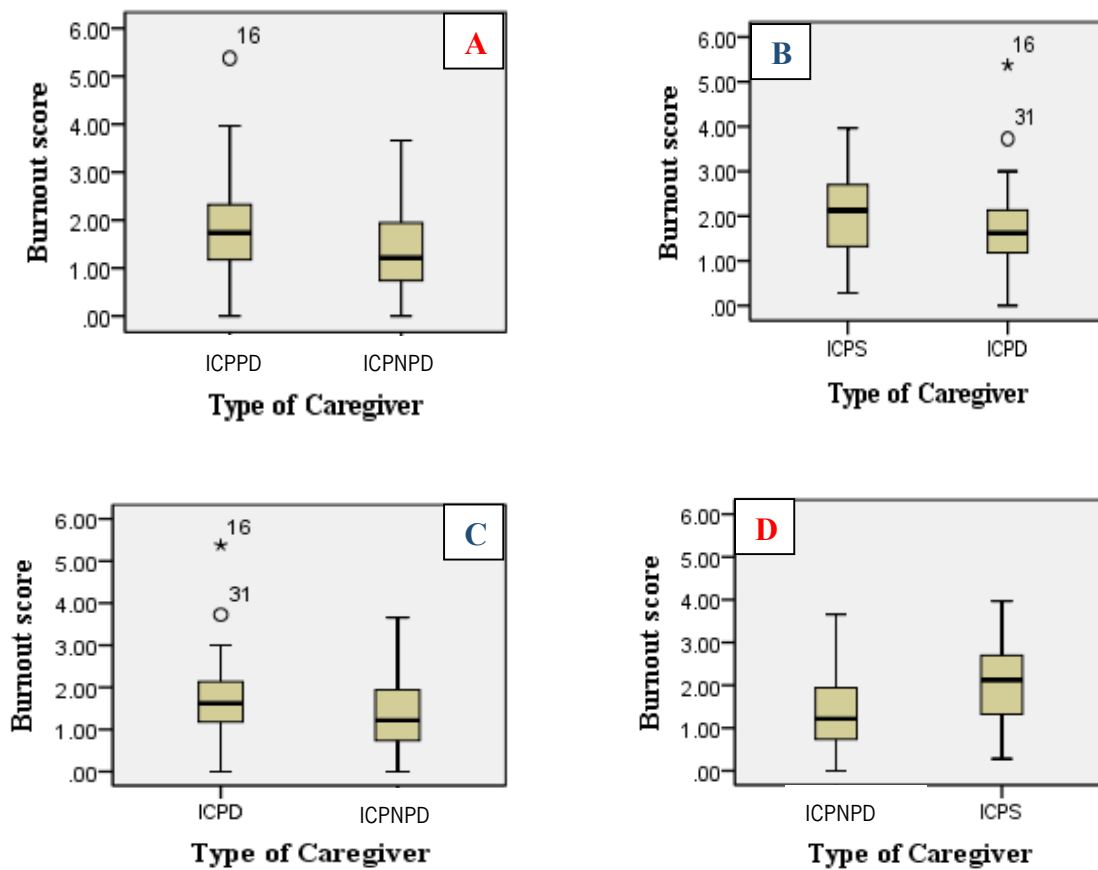


Figure 21: The Box-Plots are comparing Burnout among different groups of informal caregivers. ICPPD – Informal caregivers of patients with Psychiatric Disorder, ICPNPD – Informal Caregivers of Patients with Non-Psychiatric Disorder, ICPD – Informal Caregivers of Patients with Depression, ICPS – Informal Caregivers of Patients with Schizophrenia

4.2.1.1.2 Burnout and the Biographic variables of the caregivers (age, gender, and marital status)

For both caregivers groups, the ICPPD (**Table 18**) and ICPNPD (**Table 19**), the median of the Burnout levels were not significantly influenced by gender or age, nor by marital status.

Table 18: Comparative table of Total Burnout medians between genders, marital status and age groups of the ICPPD (Informal Caregivers of Patient with Psychiatric Disorder).

Variable	Category	TB Median	Test
Gender	Male	1.62	Mann-Whitney, U=148 $p > 0.05$, $r=0.22$
	Female	1.96	
Marital Status	Single	1.89	Mann-Whitney, U=141 $p > 0.05$, $r=0.02$
	Married	1.69	
Age groups	18-34 years	2.31	Kruskal-Wallis Test, H(2)=1.33 $p > 0.05$
	35-64 years	1.71	
	>= 65 years	1.63	

r – Effect Size. TB – Total Burnout

Table 19: Comparative table of Total Burnout medians between genders, marital status and age groups of the ICPNPD (Informal Caregivers of Patient with Non-Psychiatric Disorder).

Variable	Category	TB Median	Test
Gender	Male	1.19	Mann-Whitney, U=82 $p > 0.05$, $r=0.12$
	Female	1.22	
Marital Status	Single	1.59	Mann-Whitney, U=94.5 $p > 0.05$, $r=0.14$
	Married	1.12	
Age groups	18-34 years	1.61	Kruskal-Wallis Test, H(2)=1.2 $p > 0.05$
	35-64 years	1.08	
	>= 65 years	2.00	

r – Effect Size. TB – Total Burnout

4.2.1.1.3 Burnout and Caregiver's Education and Occupation

In both ICPPD and ICPNPD, the Burnout differences found among the different education levels and kinds of Occupation were by chance as it is illustrated in **Table 20**, **Figure 22** and **Figure 23** by the *p-Value*.

Table 20: Comparative table of Burnout medians between degrees of education and kinds of occupations of the ICPPD (Informal Caregivers of Patient with Psychiatric Disorder).

Variable	Category	Median	Kruskal-Wallis's Test
Education	4 ^o year	1.63	H(5)=3.0, $p > 0.05$
	6year	1.11	
	9 ^o year	1.73	
	12 ^o year	1.78	
	Post-secondary education	1.94	
	High education	1.81	
Occupation	Unemployed	1.96	H(4)=3.3, $p > 0.05$
	Employed Workers	1.60	
	Self-Employed	1.73	
	Retired	2.05	
	Others	2.11	

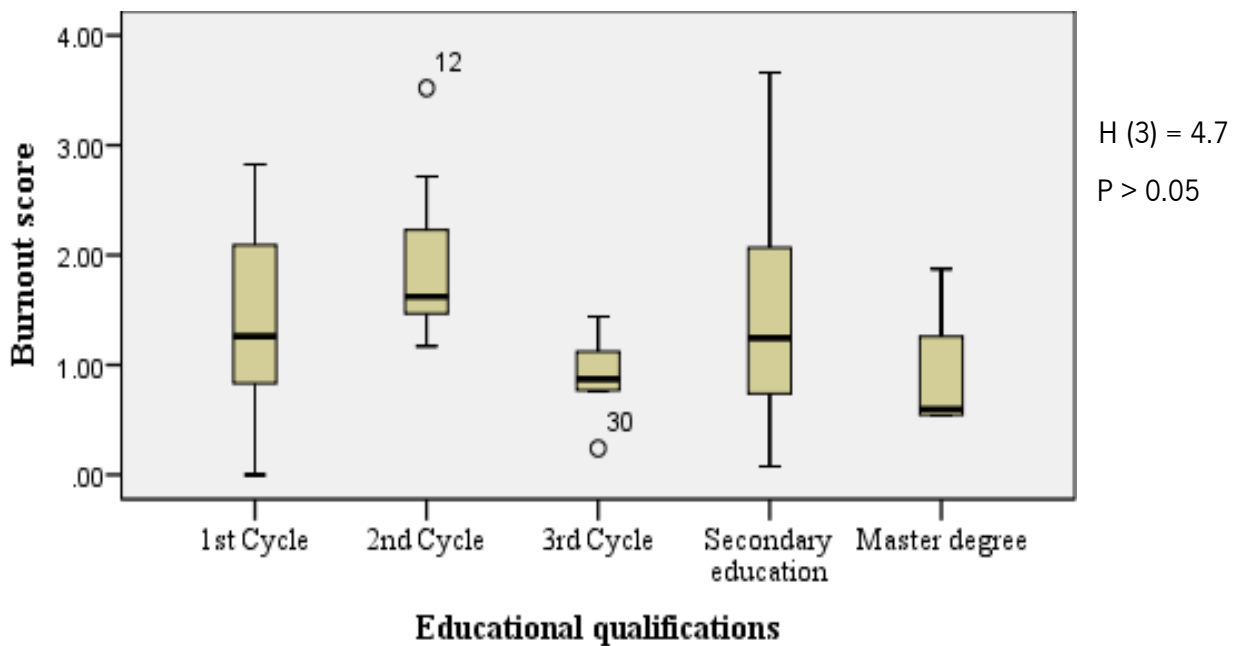


Figure 22: The Box-Plots are comparing Burnout among different levels of education of the ICPNPD (Informal Caregivers of Patients with Non-Psychiatric Disorder). H – Kruskal-Wallis Test.



Figure 23: The Box-Plots are comparing Burnout among different kinds of Occupation of the ICPNPD (Informal Caregivers of Patients with Non-Psychiatric Disorder). H – Kruskal-Wallis Test.

4.2.1.1.4 Burnout and Degree of Kinship

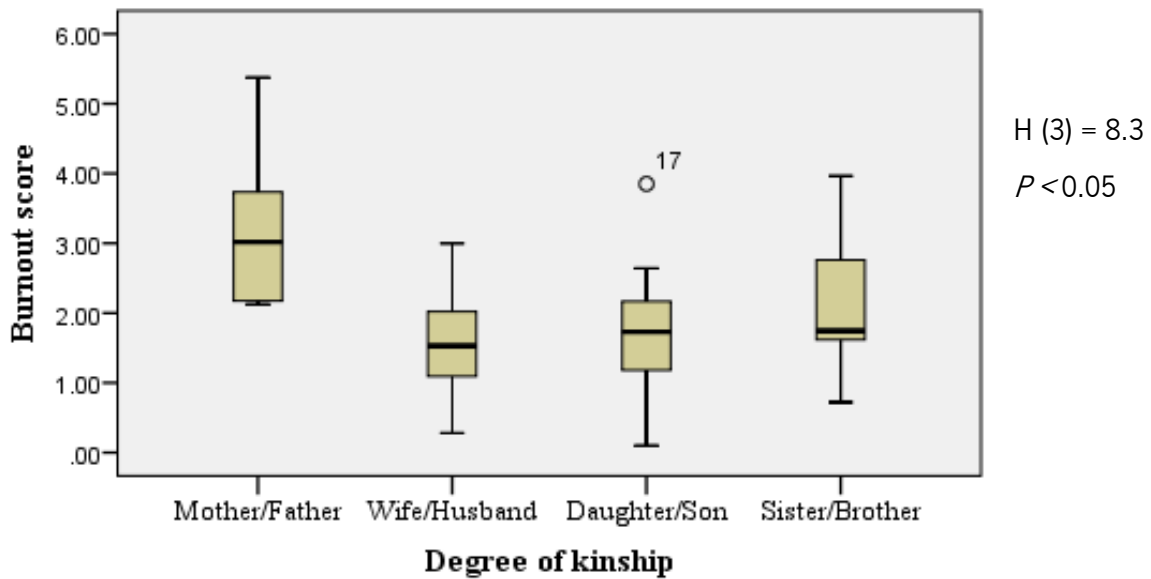


Figure 24: The Box-Plots are comparing Burnout among different degrees of kinship of the Informal caregivers of patients with Psychiatric Disorder. H – Kruskal-Wallis Test.

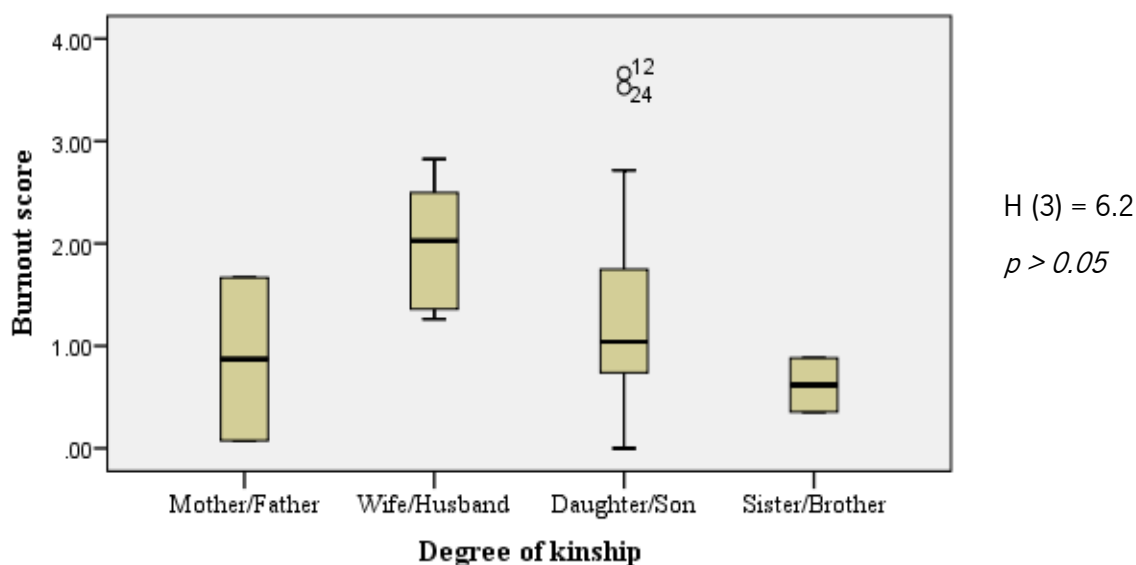


Figure 25: The Box-Plots are comparing Burnout among different degrees of kinship of the Informal Caregivers of Patients with Non-Psychiatric Disorder. H – Kruskal-Wallis Test.

The degree of kinship had a statistically significant influence among the ICPPD (**Figure 24**) but showed no influence on the levels of Burnout of the ICPNPD (**Figure 25**).

4.2.1.1.5 Burnout and Residency sharing

The residency sharing did not significantly influence the Caregiver Burnout levels in both groups (**Table 21**).

Table 21: Comparative table of burnout levels among caregivers who share the home with the sick and those who do not.

Type of IC	Variable	Category	Median	Mann-Whitney		
				U	p	Effect Size (r)
ICPPD	Residency Sharing	No	1.76	177.5	> 0.05	0.06
		Yes	1.68			
ICPNPD	Residency Sharing	No	1.00	171.0	> 0.05	0.09
		Yes	1.48			

ICPPD – Informal caregivers of patients with Psychiatric Disorder, ICPNPD – Informal Caregivers of

Patients with Non-Psychiatric Disorder, IC – Informal Caregivers, p – Significance level, U – Mann-Whitney’s test.

4.2.1.1.6 Burnout and Time Spent Annually caring for the patient

The time spent by the caregiver on patient care showed a statistically significant influence on the Burnout levels of the ICPPD, and the effect size was moderate (**Figure 26**). However, among the ICPNPD, the time spent with the patient did not influence the Burnout levels ($U = 171.0$, $p > 0.05$, $r = -0.09$).

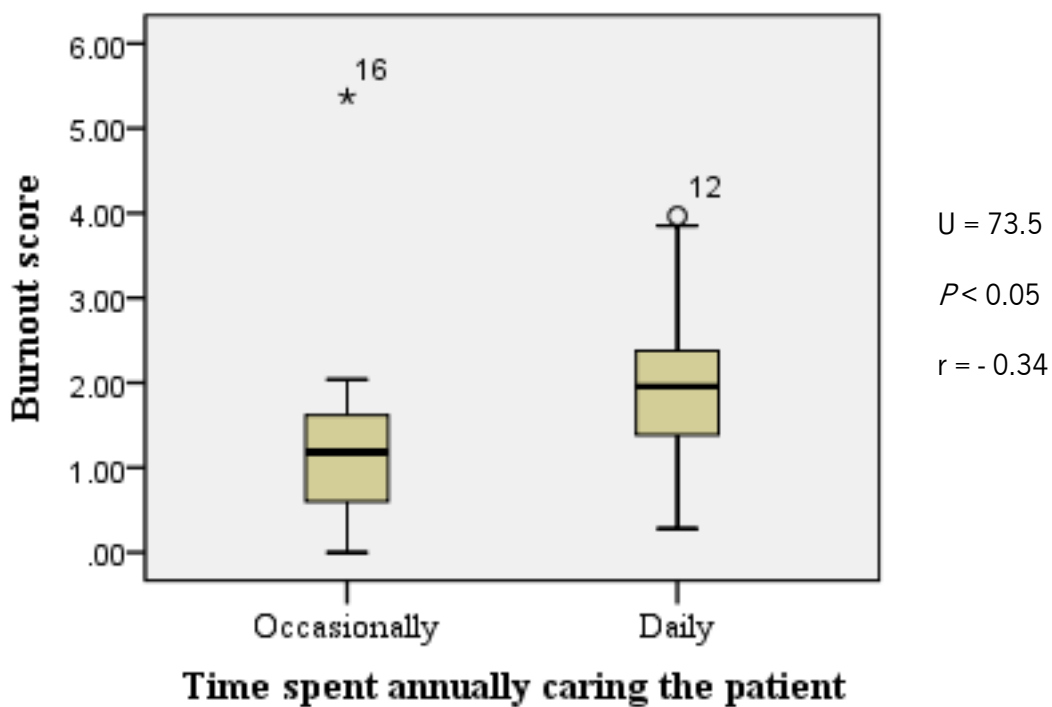


Figure 26: Box-Plot that shows the Burnout levels according to the time spent annually by Informal Caregivers of Patient with Psychiatric Disorder caring for the patient. U – Mann-Whitney’s test, p – Significance level, r – Effect Size.

4.2.1.1.7 Burnout and the Time spent daily caring for the patient

The Kruskal-Wallis test showed that in our sample the amount of time the caregiver spends per day caring for the patient does not influence the ICPPD Burnout levels ($H(4) = 2.95, p > 0.05$) or the ICPNPD Burnout levels ($H(4) = 3.39, p > 0.05$).

4.2.1.1.8 Burnout and the period as caregiver

The differences in Burnout levels between ICPPD who cared for patients for more than ten years (median = 2.13) and those who cared for a year or two (median = 1.60) were statistically significant with Mann-Whitney's test $U = 59.5, p < 0.05, r = -0.43$. The same did not occur with the ICPNPD for the same comparison groups where the Mann-Whitney's test was $U = 81.5, p > 0.05, r = -0.21$.

4.2.1.1.9 Burnout and the Family help

There were no statistically significant differences between the ICPPD who received help (median = 1.68) and those who did not receive help (median = 2.08) of the other members of the family, $U = 124, p > 0.05, r = -0.17$. The same was true among ICPNPD, $U = 125, p > 0.05, r = -0.12$.

4.2.1.1.10 Burnout and the requests for the Psychiatric and Psychological Consultation

The requests for psychological and psychiatric consultations by ICPPD and ICPNPD were by chance, not related to Burnout levels as shown in **Table 22**.

Table 22: Comparative table of burnout levels among caregivers who sought and those who did not seek psychological and psychiatric help.

Type of IC	Variable	Category	Median	Mann-Whitney		
				U	<i>p</i>	Effect Size (<i>r</i>)
ICPPD	Psychiatric Consultation	No	1.72	111.5	> 0.05	0.08
		Yes	1.84			
	Psychological Consultation	No	1.71	78.5	> 0.05	0.14
		Yes	2.06			
ICPNPD	Psychiatric Consultation	No	1.17	26.0	> 0.05	0.24
		Yes	2.72			
	Psychological Consultation	No	1.17	39.5	> 0.05	0.13
		Yes	1.61			

ICPPD – Informal caregivers of patients with Psychiatric Disorder, ICPNPD – Informal Caregivers of Patients with Non-Psychiatric Disorder, IC – Informal Caregivers, *p* – Significance level.

4.2.1.1.11 Burnout and Caregiver's Chronic Disease, Smoking habits and Alcoholic habits

The chronic illness of the caregiver influenced the Burnout levels in the ICPPD significantly. The tendency to have smoking and alcoholic habits among caregivers were not influenced by Burnout levels (**Table 23**).

Table 23: Comparative table between the Total Burnout medians according to the presence or not of chronic disease, alcoholic habit, and smoking habit.

Type of IC	Variable	Category	TB Median	Mann-Whitney		
				U	<i>p</i>	Effect Size (<i>r</i>)
ICPPD	Chronic Disease	No	1.66	121.0	< 0.05	0.30
		Yes	2.23			
	Smoking habits	No	1.66	95.5	> 0.05	0.15
		Yes	2.15			
	Alcoholic habits	No	1.73	171.0	> 0.05	0.02
		Yes	1.78			
ICPNPD	Chronic Disease	No	1.22	124.5	> 0.05	0.15
		Yes	1.33			
	Smoking habits	No	1.22	65.0	> 0.05	0.05
		Yes	1.07			
	Alcoholic habits	No	1.26	139.0	> 0.05	0.15
		Yes	0.88			

ICPPD – Informal caregivers of patients with Psychiatric Disorder, ICPNPD – Informal Caregivers of Patients with Non-Psychiatric Disorder, IC – Informal Caregivers, *p* – Significance level, TB – Total Burnout

4.2.1.1.12 Burnout dimensions and the Caregiver's groups

We did not find statistically significant differences between the different groups of IC in comparing levels of emotional exhaustion and cynicism. For the dimension Lack of Personal Accomplishment, although the levels were in general low, ICPPD had relatively high and statistically significant values when compared to ICPNPD. Among the ICPPDs the differences were not significant for this dimension (**Table 24**).

Table 24: Differences in Burnout Dimensions and their Significance in different groups of caregivers.

Variable	Categories	Median			Mann-Whitney's Test		
		EE	C	LPA	EE	C	LPA
Type of IC	ICPPD	2.4	0.8	1.0	U = 795.5 $p > 0.05$, $r = 0.00$	U = 639.5 $p > 0.05$, $r = 0.25$	U = 283.0 $p < 0.05$, $r = 0.80$
	ICPNPD	2.4	0.6	0.0			
Type of ICPPD	ICPS	3.0	1.5	1.5	U = 164.5 $p > 0.05$, $r = 0.10$	U = 143.5 $p > 0.05$, $r = 0.19$	U = 795.5 $p > 0.05$, $r = 0.09$
	ICPD	2.0	0.5	1.0			
Type of IC	ICPNPD	2.4	0.6	0.0	U = 275.5 $p > 0.05$, $r = 0.07$	U = 203.5 $p > 0.05$, $r = 0.30$	U = 88.0 $p < 0.05$, $r = 0.66$
	ICPS	3.0	1.5	1.5			
Type of IC	ICPNPD	2.4	0.6	0.0	U = 471.0 $p > 0.05$, $r = 0.06$	U = 436.0 $p > 0.05$, $r = 0.14$	U = 164.5 $p < 0.05$, $r = 0.67$
	ICPD	2.0	0.5	1.0			

IC – Informal Caregivers, ICPPD – Informal caregivers of patients with Psychiatric Disorder, ICPNPD – Informal Caregivers of Patients with Non-Psychiatric Disorder, ICPD – Informal Caregivers of Patients with Depression, ICPS – Informal Caregivers of Patients with Schizophrenia. EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, p - Significance level, r – Effect Size.

4.2.1.1.13 Burnout dimensions and the socio-demographic/clinical variables of the ICPPD

The female IC, the IC who care daily for the patient and the IC who care for the patient for more than ten years had higher and statistically significant levels of emotional exhaustion. The IC who did not share the same home with the patient had elevated levels of lack of personal accomplishment. The request for psychological help was greater in the ICPPD that had more emotional exhaustion, the presence of chronic disease and more years as caregiver caused more emotional exhaustion in the ICPPD (**Table 25**). Other variables like marital status, family help, psychiatric help, smoking, and alcoholic habits had no influence in any burnout dimensions (**Table 25**).

Table 25: Differences in Burnout Dimensions and their Significance in the ICPPD according to dichotomous socio-demographic/clinical variables.

Variable	Categories	Median			Mann-Whitney's Test		
		EE	C	LPA	EE	C	LPA
Gender	Female	3.2	1.3	0.8	U = 118.0	U = 116.0	U = 148.0
	Male	1.6	0.5	1.5	$p < 0.05$ $r = -0.35$	$p < 0.05$ $r = -0.36$	$p > 0.05$ $r = -0.22$
Marital Status	Single	1.6	1.3	1.4	U = 114.0	U = 112.5	U = 118.0
	Married	2.6	0.5	1.0	$p > 0.05$ $r = -0.16$	$p > 0.05$ $r = -0.17$	$p > 0.05$ $r = -0.14$
Residency Sharing	No	2.1	0.6	1.8	U = 167.5	U = 185.0	U = 101.5
	Yes	2.9	1.0	0.8	$p > 0.05$ $r = -0.11$	$p > 0.05$ $r = -0.13$	$p < 0.05$ $r = -0.40$
Time spent annually	Occasionally	0.8	0.5	0.8	U = 63.5	U = 95.5	U = 138.0
	Daily	3	1.3	1.0	$p < 0.05$ $r = -0.40$	$p > 0.05$ $r = -0.23$	$p > 0.05$ $r = -0.00$
Years as Caregiver	1-2	1.1	0.6	1.0	U = 61.5	U = 70.5	U = 97.5
	> 10	3	1.5	1.7	$p < 0.05$ $r = -0.36$	$p > 0.05$ $r = -0.30$	$p > 0.05$ $r = -0.14$
Family Help	No	3.6	0.8	1.5	U = 107.0	U = 149.5	U = 159.5
	Yes	2	1.0	1.0	$p > 0.05$ $r = -0.01$	$p > 0.05$ $r = -0.12$	$p > 0.05$ $r = -0.00$
Psychiatric Help	No	2.0	0.9	1.0	U = 93.5	U = 121.5	U = 92.5
	Yes	3.4	1.0	0.7	$p > 0.05$ $r = -0.19$	$p > 0.05$ $r = -0.04$	$p > 0.05$ $r = -0.18$
Psychological Help	No	1.9	0.9	1.0	U = 50.0	U = 96.0	U = 69.5
	Yes	3.7	1.0	0.7	$p < 0.05$ $r = -0.31$	$p > 0.05$ $r = -0.03$	$p > 0.05$ $r = -0.19$
Chronic Disease	No	1.9	0.5	0.9	U = 121.0	U = 142.5	U = 173.5
	Yes	3.5	1.3	1.0	$p < 0.05$ $r = -0.31$	$p > 0.05$ $r = -0.22$	$p > 0.05$ $r = -0.08$
Smoking Habits	No	2.3	0.6	0.9	U = 105.5	U = 126.0	U = 110.5
	Yes	3.4	1.1	1.6	$p > 0.05$ $r = -0.13$	$p > 0.05$ $r = -0.01$	$p > 0.05$ $r = -0.09$
Alcoholic Habits	No	2.6	1.3	1.0	U = 160.0	U = 137.0	U = 198.5
	Yes	1.8	0.5	1.0	$p > 0.05$ $r = -0.17$	$p > 0.05$ $r = -0.27$	$p > 0.05$ $r = -0.15$

ICPPD – Informal caregivers of patients with Psychiatric Disorder, EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment.

Variables such as age groups, education levels, types of the profession and the time spent daily caring for the patient were shown to have no influence in any Burnout dimensions of the ICPPD. Only the

degree of kinship showed to have a statistically significant influence on the level of cynicism, highlighting the degrees of kinships, parent, and children with higher levels of cynicism in our sample (**Table 26**).

Table 26: Differences in Burnout Dimensions and their Significance in the ICPPD according to the socio-demographic variables with more than two categories.

Variable	Categories	Median			Kruskal-Wallis Test		
		EE	C	LPA	EE	C	LPA
Age groups	18-34 years	2.0	1.3	1.0	H(2) = 0.3 $p > 0.05$	H(2) = 3.7 $p > 0.05$	H(2) = 2.6 $p > 0.05$
	35-64 years	2.5	0.4	0.8			
	More than 65	2.4	1.0	2.8			
Education	1 st Cycle	3.8	0.3	0.6	H(6) = 4.4 $p > 0.05$	H(6) = 6.3 $p > 0.05$	H(6) = 5.4 $p > 0.05$
	2 st Cycle	2.0	0.1	0.9			
	3 st Cycle	3.2	1.3	1.0			
	2 nd education	3.4	0.8	0.6			
	Post-2 nd education	2.6	1.4	1.3			
	High education	1.6	0.6	1.4			
Occupation	Unemployed	3.2	1.3	0.5	H(4) = 2.0 $p > 0.05$	H(4) = 3.6 $p > 0.05$	H(4) = 3.3 $p > 0.05$
	Employed Workers	1.8	0.8	0.8			
	Self-Employed	2.2	0.1	1.3			
	Retired	3.1	0.9	2.3			
	Others	2.7	2.0	1.4			
Degree of Kinship	Husband/Wife	2.3	0.3	0.8	H(6) = 7.8 $p > 0.05$	H(6) = 15 $p < 0.05$	H(6) = 7.0 $p > 0.05$
	Father/Mother	4.9	3.0	1.2			
	Son/Daughter	1.8	1.3	1.3			
	Brother/Sister	2.4	0.5	2.5			
	Others	3.3	0.4	1.0			
Time Spend Daily	< 1 hour	1.0	0.5	0.6	H(4) = 3.9 $p > 0.05$	H(4) = 4.3 $p > 0.05$	H(4) = 1.3 $p > 0.05$
	1 to 2 hours	2.4	0.8	1.5			
	2 to 3 hours	2.3	1.3	1.6			
	3 to 5 hours	4.5	2.1	1.8			
	> 5 hours	3.3	1.3	0.8			

ICPPD – Informal caregivers of patients with Psychiatric Disorder, EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment.

4.2.1.1.14 Burnout dimensions and the socio-demographic variables of the ICPNPD

Most of the socio-demographic variables of the ICPNPD evaluated did not show a significant influence on the levels of emotional exhaustion, cynicism and personal accomplishment as shown in **Table 27**, **Table 28**, **Table 29** and **Table 30**. Only the variables Age group (**Table 29**) and Time spent daily (**Table 30**) caring for the patient proved to have a significant influence on personal accomplishment. In our sample, the ICPNPD with the highest levels of cynicism were who sought help from a psychologist.

Table 27: Differences in Burnout Dimensions and their Significance in the ICPNPD according to dichotomous socio-demographic variables.

Variable	Categories	Median			Mann-Whitney's Test		
		EE	C	LPA	EE	C	LPA
Gender	Female	2.5	0.8	0.0	U = 79.0	U = 70.5	U = 85.0
	Male	1.7	0.3	0.2	$p > 0.05$ $r = -0.14$	$p > 0.05$ $r = -0.19$	$p > 0.05$ $r = -0.11$
Marital Status	Single	1.9	0.6	0.3	U = 111.5	U = 85.5	U = 93.5
	Married	2.4	0.5	0.0	$p > 0.05$ $r = -0.02$	$p > 0.05$ $r = -0.18$	$p > 0.05$ $r = -0.14$
Residency Sharing	No	1.9	0.1	0.0	U = 154.5	U = 174.5	U = 181.5
	Yes	2.6	0.8	0.0	$p > 0.05$ $r = -0.15$	$p > 0.05$ $r = -0.08$	$p > 0.05$ $r = -0.05$
Time spent annually	Occasionally	1.7	0.9	0.1	U = 108.5	U = 105.5	U = 127.0
	Daily	2.6	0.6	0.0	$p > 0.05$ $r = -0.20$	$p > 0.05$ $r = -0.23$	$p > 0.05$ $r = -0.13$
Years as Caregiver	1-2	2.6	0.8	0.0	U = 86.5	U = 82.0	U = 102.0
	> 10	1.8	0.3	0.0	$p > 0.05$ $r = -0.15$	$p > 0.05$ $r = -0.18$	$p > 0.05$ $r = -0.06$
Family Help	No	3.3	0.6	0.3	U = 121.5	U = 140.0	U = 111.5
	Yes	2.3	0.6	0.0	$p > 0.05$	$p > 0.05$	$p > 0.05$
	Yes	1.8	0.3	0.0	$r = -0.14$	$r = -0.05$	$r = -0.20$

ICPNPD – Informal Caregivers of Patients with Non-Psychiatric Disorder, EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment.

Table 28: Differences in Burnout Dimensions and their Significance in the ICPNPD according to dichotomous clinical variables.

Variable	Categories	Median			Mann-Whitney's Test		
		EE	C	LPA	EE	C	LPA
Psychiatric Help	No	2.4	0.5	0.0	U = 23.0 $p > 0.05$ $r = -0.26$	U = 46.0 $p > 0.05$ $r = -0.08$	U = 34.5 $p > 0.05$ $r = -0.19$
	Yes	5.4	0.8	0.8			
Psychological Help	No	2.4	0.5	0.0	U = 49.0 $p > 0.05$ $r = -0.05$	U = 12.5 $p < 0.05$ $r = -0.36$	U = 55.0 $p > 0.05$ $r = -0.00$
	Yes	2.4	1.5	0.0			
Chronic Disease	No	2.4	0.8	0.0	U = 128.0 $p > 0.05$ $r = -0.00$	U = 121.5 $p > 0.05$ $r = -0.04$	U = 113.0 $p > 0.05$ $r = -0.10$
	Yes	2.4	0.5	0.1			
Smoking Habits	No	2.4	0.6	0.0	U = 67.0 $p > 0.05$ $r = -0.13$	U = 61.5 $p > 0.05$ $r = -0.08$	U = 36.0 $p > 0.05$ $r = -0.01$
	Yes	2.3	0.8	0.0			
Alcoholic Habits	No	2.6	0.8	0.0	U = 127.0 $p > 0.05$ $r = -0.22$	U = 116.5 $p > 0.05$ $r = -0.27$	U = 155.5 $p > 0.05$ $r = -0.10$
	Yes	1.8	0.3	0.0			

ICPNPD – Informal Caregivers of Patients with Non-Psychiatric Disorder, EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment.

Table 29: Differences in Burnout Dimensions and their Significance in the ICPNPD according to the socio-demographic variables with more than two categories.

Variable	Categories	Median			Kruskal-Wallis Test		
		EE	C	LPA	EE	C	LPA
Age groups	18-34 years	2.0	1.0	0.7	H(2) = 2.9 $p > 0.05$	H(2) = 3.4 $p > 0.05$	H(2) = 6.0 $p < 0.05$
	35-64 years	2.1	0.3	0.0			
	More than 65	2.4	0.8	0.2			
Education	1 st Cycle	2.6	0.8	0.0	H(4) = 4.8 $p > 0.05$	H(4) = 8.3 $p > 0.05$	H(4) = 2.9 $p > 0.05$
	2 st Cycle	3.4	0.8	0.0			
	3 st Cycle	1.8	0.0	0.0			
	2 nd education	2.1	0.9	0.3			
	Master degree	1.4	0.1	0.3			
Occupation	Unemployed	3.0	0.8	0.0	H(4) = 0.8 $p > 0.05$	H(4) = 1.6 $p > 0.05$	H(4) = 5.9 $p > 0.05$
	Employed Workers	2.0	0.6	0.0			
	Self-Employed	1.8	0.8	0.0			
	Retired	2.5	0.5	0.22			
	Others	3.0	1.6	2.6			

ICPNPD – Informal Caregivers of Patients with Non-Psychiatric Disorder, EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment.

Table 30: Differences in Burnout Dimensions and their Significance in the ICPNPD according to the socio-demographic variables with more than two categories.

Variable	Categories	Median			Kruskal-Wallis Test		
		EE	C	LPA	EE	C	LPA
Degree of Kinship	Husband/Wife	4.5	0.9	0.2	H(6) = 8.9 $p > 0.05$	H(6) = 5.7 $p > 0.05$	H(6) = 4.6 $p > 0.05$
	Father/Mother	1.8	0.5	0.0			
	Son/Daughter	2.3	0.4	0.1			
	Brother/Sister	1.2	0.4	0.1			
	Others	1.6	0.0	0.0			
Time Spend Daily	< 1 hour	1.4	0.8	0.5	H(3) = 2.4 $p > 0.05$	H(3) = 4.2 $p > 0.05$	H(3) = 9.6 $p < 0.05$
	1 to 2 hours	3.1	2.0	0.8			
	2 to 3 hours	1.7	0.9	0.1			
	3 to 5 hours	1.7	0.0	0.1			
	> 5 hours	2.7	0.3	0.0			

ICPNPD – Informal Caregivers of Patients with Non-Psychiatric Disorder, EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment.

4.2.1.1.15 Burnout and the Socio-demographic variables of the Patient

The ICPPD of single patients showed higher and statistically significant levels of Burnout and emotional exhaustion compared to those caring for married patients. Retired patients were related to higher levels of cynicism in the caregiver than those who still worked. The Variables, gender, and age of the patient showed no significant influence on Burnout in our sample (**Table 31**).

Regarding the ICPNPD, only the variable Marital Status had a significant influence on Burnout and its dimensions, where the ICs that care for married patients had more emotional exhaustion, cynicism, and Burnout. Burnout variations related to variables age, gender, and type of occupation were not statistically significant (**Table 32**).

Table 31: Burnout, EE, C, and LPA differences within the Age groups, Genders, Civil status and Types of occupations of the ICPPD.

Patient Variable	Categories	Median				Significance level			
		EE	C	LPA	TB	EE	C	LPA	TB
Age group	18-34 years	4.4	1.5	1.0	2.3	H ₍₂₎ = 2.7	H ₍₂₎ = 5.7	H ₍₂₎ = 2.6	H ₍₂₎ = 2.8
	35-64 years	2.3	0.9	1.4	1.7	$p > 0.05$	$p > 0.05$	$p > 0.05$	$p > 0.05$
	More than 65	1.8	0.0	0.7	1.6				
Gender	Female	2.1	0.9	1.0	1.8	U = 20.0	U = 27.5	U = 92.5	U = 23.5
	Male	2.9	1.0	0.7	1.8	$p > 0.05$ $r = -0.04$	$p > 0.05$ $r = 0.00$	$p > 0.05$ $r = -0.19$	$p > 0.05$ $r = 0.0$
Marital status	Single	4.2	1.5	1.5	2.6	U = 50.0	U = 59.0	U = 92.0	U = 47.0
	Married	2.0	0.5	1.0	1.6	$p < 0.05$ $r = -0.31$	$p > 0.05$ $r = -0.25$	$p > 0.05$ $r = -0.00$	$p < 0.05$ $r = -0.35$
Occupation	Employed Workers	1.6	1.3	1.3	1.6	U = 62.5	U = 37.5	U = 41.0	U = 49.5
	Retired	1.8	0.0	0.7	1.6	$p > 0.05$ $r = -0.00$	$p < 0.05$ $r = -0.32$	$p > 0.05$ $r = -0.28$	$p > 0.05$ $r = -0.20$

EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, TB – Total Burnout, H – Kruskal-Wallis test, U – Mann-Whitney’s test, ICPPD – Informal Caregivers of Patient with Psychiatric Disorder.

Table 32: Burnout, EE, C, and LPA differences within the Age groups, Genders, Civil status and Types of occupations of the ICPNPD.

Patient Variable	Categories	Median				Significance level			
		EE	C	LPA	TB	EE	C	LPA	TB
Age group	18-34 years	1.8	0.5	0.0	0.9	H ₍₂₎ = 0.6	H ₍₂₎ = 2.0	H ₍₂₎ = 2.4	H ₍₂₎ = 0.6
	35-64 years	2.8	0.0	0.0	1.1	$p > 0.05$	$p > 0.05$	$p > 0.05$	$p > 0.05$
	> 65	2.4	1.1	0.0	1.2				
Gender	Female	2.0	0.5	0.0	1.0	U = 103.5	U = 118.0	U = 147.5	U = 96.0
	Male	3.4	1.0	0.0	2.1	$p > 0.05$ $r = -0.26$	$p > 0.05$ $r = 0.20$	$p > 0.05$ $r = -0.00$	$p > 0.05$ $r = 0.31$
Marital status	Married	4.2	1.0	0.2	2.1	U = 91.0	U = 101.0	U = 146.0	U = 83.0
	Widower	1.9	0.3	0.0	1.0	$p < 0.05$ $r = 0.36$	$p < 0.05$ $r = 0.32$	$p > 0.05$ $r = 0.10$	$p < 0.05$ $r = 0.40$
Occupation	Retired	2.2	0.6	0.0	1.1	U = 77.0	U = 71.5	U = 62.5	U = 72.0
	Invalid	2.6	0.5	0.4	1.2	$p > 0.05$ $r = -0.04$	$p > 0.05$ $r = -0.10$	$p > 0.05$ $r = -0.15$	$p > 0.05$ $r = -0.10$

EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, TB – Total Burnout, H – Kruskal-Wallis test, U – Mann-Whitney’s test, ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder.

4.2.1.1.16 *Burnout and the Barthel Index Levels*

Regarding the basic activities of daily living, the Burnout differences related to the patient dependency levels using the Barthel Index scale were not statistically significant for either ICPPD (Mann-Whitney U = 68.0, $p > 0.05$, $r = 0.03$) or for ICPNPD (Kruskal-Wallis H 3) = 1.5, $p > 0.05$) as shown in **Figure 27**.

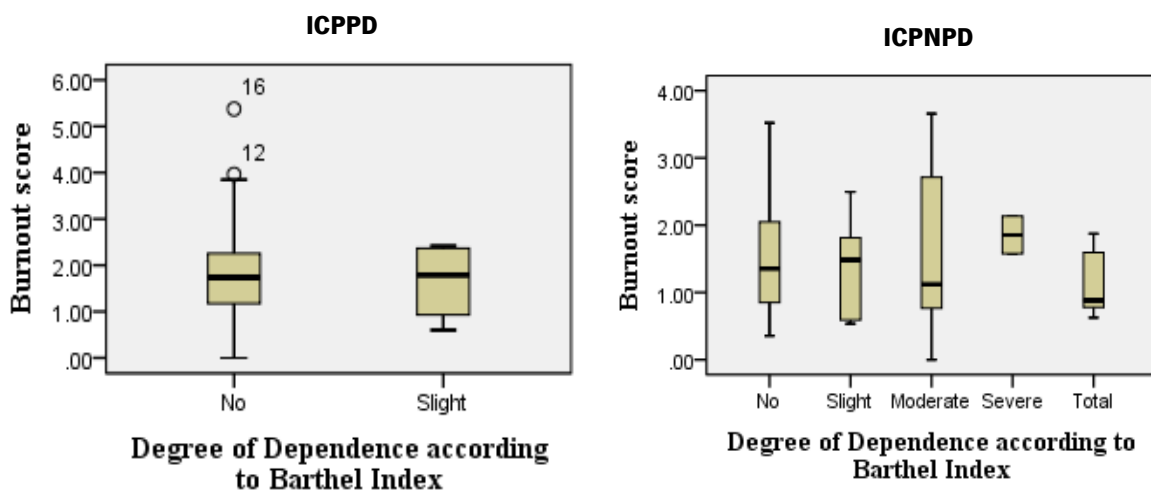


Figure 27: The Box-Plots are indicating the differences in the Caregivers Burnout score between different degrees of patient dependence on basic activities of daily living. ICPPD – Informal Caregivers of Patient with Psychiatric Disorder, ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder.

4.2.1.1.17 *Burnout and the Lawton Index levels*

In comparing the burnout levels of caregivers according to patient dependence on instrumental activities of daily living (using the Lawton Index scale), ICPPD showed statistically significant differences

in Burnout levels between different degrees of patient dependence ($H(2) = 7.9, p < 0.05$) while the ICPNPD didn't show any significant differences ($H(2) = 0.2, p > 0.05$) as shown in **Figure 28**.

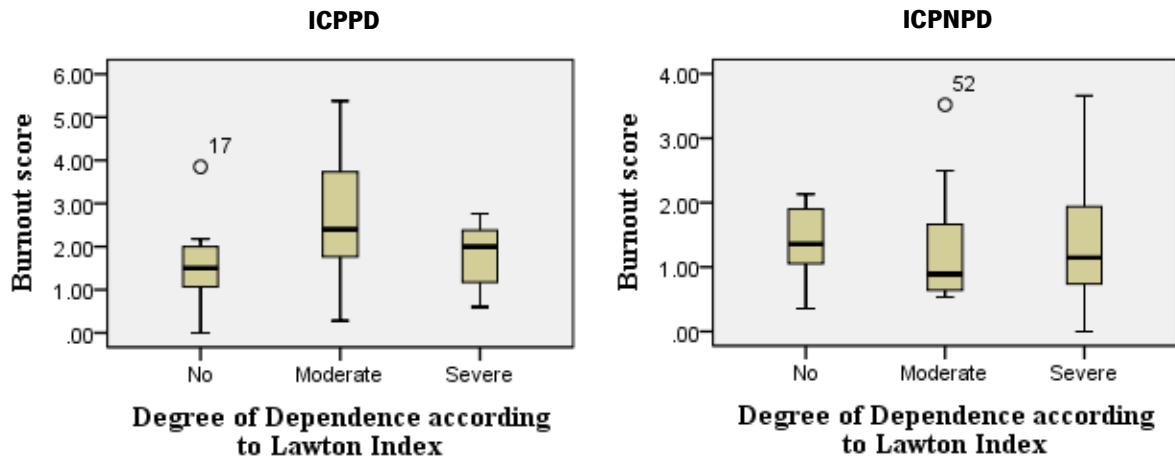


Figure 28: The Box-Plots are indicating the differences in the Caregivers Burnout score between different degrees of patient dependence on instrumental activities of daily living. ICPPD – Informal Caregivers of Patient with Psychiatric Disorder, ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder.

4.2.1.2 Stress

The median of the Perceived Stress in ICPPD was 26 and for ICPNPD was 25, the difference between them was not statistically significant ($U = 668.0, p > 0.05, r = 0.21$).

Among the ICPPD, the Stress score had a statistically significant relationship ($U = 106.5, p < 0.05, r = 0.40$) only with the variable, Caregiver's gender. Female caregivers had a higher median of the Stress score (median = 28) compared to male caregivers (median = 25).

Within the ICPNPD, only the variable Smoking habits of the Caregiver had a statistically significant relationship ($U = 27.5, p < 0.05, r = 0.32$) with the variable Stress, where the median of the Stress score of the Non-smokers was higher (median = 25) compared to the Smokers (median = 18).

The socio-demographic variables and the degree of dependency of the patient showed a non-significant relationship with the Caregiver's stress.

4.2.1.3 Coping strategies

The perceived effectiveness of the coping strategies chosen to deal with the difficulties of being a caregiver was not different between the two groups of caregivers ($U = 777.4$, $p > 0.05$, $r = 0.03$). The median of the degree of the coping strategies efficiency for ICPPD was 112, and for ICPNPD it was 109.

The socio-demographic/clinical variables of the caregiver that showed a statistically significant relationship with the degree of the coping strategies efficiency chosen were: Age, Marital Status, Education, Alcoholic and Smoking habits.

Regarding the socio-demographic variables of the patient, none showed a significant relationship with the degree of the efficiency of the coping strategies.

4.2.1.3.1 Coping Strategies and Age Groups

Table 33: The table shows the differences between the medians of the categories of socio-demographic variables.

Type of Caregiver	Age groups	Median of the AP score	Kruskal-Wallis	
			H (2)	p
ICPPD	18-34	45	6.3	< 0.05
	35-64	43		
	>65	39		
ICPNPD	18-34	43	7.4	< 0.05
	35-64	47		
	>65	47		

ICPPD – Informal Caregivers of Patient with Psychiatric Disorder); ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; AP – Alternative Perception; H – Kruskal-Wallis test; r – Effect Size; p – Significance level.

The ICPPD aged less than 35 years had a high perception of efficiency in the use of coping strategy related to the category Alternative perception of difficult situations, in comparisons with caregivers of middle age and the elderly. However, in ICPNPD, young people had an impression of less efficiency for the same strategies, as demonstrated by the Kruskal-Wallis test (**Table 33**).

4.2.1.3.2 Coping strategies and marital status

Single caregivers had a high perceived efficiency in coping strategies related to category dealing with stress symptoms (such as crying a little, unloading the tension speaking loudly) compared to married couples (**Table 34**).

Table 34: The table shows the differences between the medians of the categories of socio-demographic variables.

Type of Caregiver	Marital status	Median of the DS-score	Mann-Whitney		
			U	<i>p</i>	<i>r</i>
ICPPD	Single	26	79.5	<0.05	- 0.33
	Married	20			
ICPNPD	Single	24	64.5	<0.05	- 0.32
	Married	20			

ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; DS – Dealing with stress; U – Mann-Whitney's test; *r* – Effect Size; *p* – Significance level.

4.2.1.3.3 Coping strategies and education

The education variable showed a relationship with the category of Dealing with events and solving problems only in the ICPNPD, where the caregivers with more level of education had a greater perception of the efficiency of coping strategies of this category (**Table 35**).

Table 35: The table shows the differences between the medians of the categories of socio-demographic variables.

Type of Caregiver	Education	Median of the DE/SP score	Kruskal-Wallis	
			H (4)	<i>p</i>
ICPPD	4 ^o year	43	9.5	< 0.05
	6 ^o year	38		
	9 ^o year	38		
	12 ^o year	47		
	Master degree	50		

ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; DE/SP – Dealing with Events/Solving Problem; H – Kruskal-Wallis test; *r* – Effect Size; *p* – Significance level.

4.2.1.3.4 Coping Strategies and Smoking Habits

Table 36: The table shows the differences between the medians of the categories of socio-demographic variables.

Type of Caregiver	Smoking Habits	Median of the AP score	Mann-Whitney		
			U	<i>p</i>	<i>r</i>
ICPPD	No	43	45.5	< 0.05	- 0.44
	Yes	45			
ICPNPD	No	45	27.5	< 0.05	- 0.32
	Yes	54			

ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; AP – Alternative Perception; U – Mann-Whitney's test; *r* – Effect Size; *p* – Significance level.

The smokers of the ICPNPD group had a greater perception of efficiency in the coping strategies of the category Dealing with stress and problem-solving (median = 49) compared to smokers (median = 43), U = 8.5, *p* < 0.5, *r* = - 0.46.

About the category Alternative perception of the situation, smokers showed a better perception of the efficiency of these strategies in ICPPD as well as ICPNPD (**Table 36**).

Smokers belonging to the ICPNPD group had a higher perception of the efficiency of the total CAMI coping strategies compared to nonsmokers, $U = 16$, $p < 0.05$, $r = -0.40$. In the ICPPD group, there were no differences.

The ICPNPD with alcoholic habits had a greater perception of the efficiency of the total CAMI coping strategies than those who did not have these habits ($U = 94.5$, $p < 0.05$, $r = -0.37$), especially in the category of Dealing with events and Problem solving ($U = 104$, $p < 0.05$, $r = -0.33$).

4.2.1.4 Stigma

The level of the stigma of Psychiatric Disorder by ICPNPD was similar to that of ICPPD whose value was 3.0 on a scale of 1 to 9 ($U=733.0$, $p > 0.05$, $r = 0.11$). There were also no differences in the dimensions or stereotypes of the stigma scale (AQ27) between the two groups.

The socio-demographic variables showed no significant influence on the total stigma and its dimensions.

4.2.2 Correlation between Burnout and Predictive Variables

To study the correlations between Burnout (as well as its dimensions) with the independent variables, we used as predictor variables the age of the caregiver and the patient, the gender, the degree of dependence of the patient, the number of readmissions, the number of the days of hospitalization, coping strategies, stress, and stigma. Because most of the variables were not normally distributed in ICPPD as well as ICPNPD, Spearman's rank- order correlation was used to analyze the data.

4.2.2.1 Correlation between Burnout and Caregivers/Patient's age

We did not find any influence of the variable age on the caregiver's Total Burnout nor its dimensions in both groups of caregivers. The variable age of the patient had a moderate and inverse correlation with the Total Burnout, emotional exhaustion, and cynicism of the ICPPD but had no impact on the ICPNPD (**Table 37**).

Table 37: The table is showing the correlation between Burnout and its dimensions with the variable Age.

Type of Caregiver	Dependent variable	Independent variable	
		Caregiver's age	Patient's age
ICPPD	TB	$r_s = 0.19, p > 0.05$	$r_s = -0.35, p < 0.05$
	EE	$r_s = 0.18, p > 0.05$	$r_s = -0.35, p < 0.05$
	C	$r_s = -0.05, p > 0.05$	$r_s = -0.56, p < 0.05$
	LPA	$r_s = 0.16, p > 0.05$	$r_s = -0.04, p > 0.05$
ICPNPD	BT	$r_s = -0.044, p > 0.05$	$r_s = -0.11, p > 0.05$
	EE	$r_s = 0.09, p > 0.05$	$r_s = -0.10, p > 0.05$
	C	$r_s = -0.27, p > 0.05$	$r_s = -0.11, p > 0.05$
	LPA	$r_s = -0.06, p > 0.05$	$r_s = -0.07, p > 0.05$

EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, TB – Total Burnout, ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; r_s - Spearman's rank- order correlation, p – Significance level.

4.2.2.2 Correlation between Burnout and Caregivers/Patient's gender

The variable gender of the caregiver only had a correlation with the emotional exhaustion and cynicism dimensions of the ICPPD, with no influence of the same in the ICPNPD. The variable gender of the patient had no significant impact on Burnout in both groups (**Table 38**).

Table 38: The table is showing the correlation between Burnout and its dimensions with the variable Gender.

Type of Caregiver	Dependent variable	Independent variable	
		Caregiver's gender	Patient's gender
ICPPD	TB	$r_s = -0.22, p > 0.05$	$r_s = -0.03, p > 0.05$
	EE	$r_s = -0.35, p < 0.05$	$r_s = 0.04, p > 0.05$
	C	$r_s = -0.36, p < 0.05$	$r_s = -0.01, p > 0.05$
	LPA	$r_s = 0.22, p > 0.05$	$r_s = -0.19, p > 0.05$
ICPNPD	BT	$r_s = -0.12, p > 0.05$	$r_s = 0.31, p > 0.05$
	EE	$r_s = -0.14, p > 0.05$	$r_s = 0.27, p > 0.05$
	C	$r_s = -0.19, p > 0.05$	$r_s = 0.20, p > 0.05$
	LPA	$r_s = 0.13, p > 0.05$	$r_s = 0.06, p > 0.05$

EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, TB – Total Burnout, ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; r_s - Spearman's rank- order correlation, p – Significance level.

4.2.2.3 Correlation between Burnout and the readmissions number

We found a moderate and inverse correlation of the readmissions' number of the patient only with the cynicism dimension of the ICPPD. Concerning the ICPNPD, the Total Burnout and its dimensions were not affected by the number of readmissions (**Table 39**).

Table 39: The table is showing the correlation between Burnout and its dimensions with the variable Readmissions' number.

Type of Caregiver	Dependent variable	Independent variable
		Readmissions' number
ICPPD	BT	$r_s = -0.30, p > 0.05$
	EE	$r_s = 0.16, p > 0.05$
	C	$r_s = -0.31, p < 0.05$
	LPA	$r_s = 0.15, p > 0.05$
ICPNPD	BT	$r_s = -0.15, p > 0.05$
	EE	$r_s = 0.21, p > 0.05$
	C	$r_s = -0.07, p > 0.05$
	LPA	$r_s = -0.13, p > 0.05$

EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, TB – Total Burnout, ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; r_s - Spearman's rank- order correlation, p – Significance level.

4.2.2.4 Correlation between Burnout and the days of hospitalization

Table 40: The table is showing the correlation between Burnout and its dimensions with the variable Days of hospitalization.

Type of Caregiver	Dependent variable	Independent variable
		Days of Hospitalization
ICPPD	BT	$r_s = -0.19, p > 0.05$
	EE	$r_s = 0.08, p > 0.05$
	C	$r_s = -0.12, p > 0.05$
	LPA	$r_s = 0.11, p > 0.05$
ICPNPD	BT	$r_s = -0.01, p > 0.05$
	EE	$r_s = 0.03, p > 0.05$
	C	$r_s = -0.09, p > 0.05$
	LPA	$r_s = -0.19, p > 0.05$

EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, TB – Total Burnout, ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder r_s - Spearman's rank- order correlation, p – Significance level.

The days of hospitalization had no influence on the total burnout levels or their dimensions in both groups of caregivers in our sample (**Table 40**).

4.2.2.5 Correlation between Burnout and the Level of Patient dependence

We did not verify any influence of the basic activities of daily life (Barthel Index) in the levels of Total Burnout and its dimensions in the two groups of caregivers. The dependence of patient for instrumental activities of daily living (Lawton Index) had a moderate and a positive correlation with the Total Burnout in the ICPPD but not with its dimensions. Concerning ICPNPD, patient dependence on instrumental activities only had an inverse and moderate correlation with the cynicism dimension (**Table 41**).

Table 41: The table is showing the correlation between Burnout and its dimensions with the variable Barthel e Lawton Index.

Type of Caregiver	Dependent variable	Independent variable	
		Barthel Index	Lawton Index
ICPPD	BT	$r_s = 0.04, p > 0.05$	$r_s = 0.34, p < 0.05$
	EE	$r_s = 0.02, p > 0.05$	$r_s = -0.27, p > 0.05$
	C	$r_s = -0.02, p > 0.05$	$r_s = -0.17, p > 0.05$
	LPA	$r_s = 0.15, p > 0.05$	$r_s = -0.06, p > 0.05$
ICPNPD	BT	$r_s = -0.04, p > 0.05$	$r_s = -0.15, p > 0.05$
	EE	$r_s = 0.00, p > 0.05$	$r_s = -0.07, p > 0.05$
	C	$r_s = -0.15, p > 0.05$	$r_s = -0.35, p < 0.05$
	LPA	$r_s = -0.02, p > 0.05$	$r_s = -0.04, p > 0.05$

EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, TB – Total Burnout, ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; r_s - Spearman's rank- order correlation, p – Significance level.

4.2.2.6 Correlation between Burnout and Stress

The levels of Stress of the ICPPD did not show a significant relationship with Burnout levels and their dimensions. Regarding ICPNPD, stress had a positive and moderate influence on the levels of Total Burnout, Emotional Exhaustion and Lack of Personal Accomplishment, and had no effect on cynicism (**Table 42**).

Table 42: The table is showing the correlation between Burnout and its dimensions with the variable Stress.

Type of Caregiver	Dependent variable	Independent variable
		Stress
ICPPD	BT	$r_s = 0.12, p > 0.05$
	EE	$r_s = 0.29, p > 0.05$
	C	$r_s = 0.28, p > 0.05$
	LPA	$r_s = -0.17, p > 0.05$
ICPNPD	BT	$r_s = 0.43, p < 0.05$
	EE	$r_s = 0.35, p < 0.05$
	C	$r_s = 0.26, p > 0.05$
	LPA	$r_s = 0.44, p < 0.05$

EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, TB – Total Burnout, ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; r_s - Spearman's rank- order correlation, p – Significance level.

4.2.2.7 Correlation between the Burnout and The CAMI scale

Regarding the CAMI variable and its dimensions, only the dimension Dealing with events / Problem Solving showed a moderate and a significant tendency to reduce emotional exhaustion among ICPPD (**Table 43**).

Among the ICPNPD, the CAMI itself and the Dealing with events / Problem Solving and Alternative perception dimensions had effects on the reduction of the Total Burnout. The Alternative perception dimension also had effects in reducing the degree of cynicism (**Table 43**).

Table 43: The table is showing the correlation between Burnout and its dimensions with the variable CAMI and its dimensions.

Type of Caregiver	Dependent variable	Independent variable			
		DE/PS	AP	DS	CAMI
ICPPD	BT	$r_s = -0.17$ $p > 0.05$	$r_s = -0.34$ $p > 0.05$	$r_s = -0.06$ $p > 0.05$	$r_s = -0.18$ $p > 0.05$
	EE	$r_s = -0.32$ $p < 0.05$	$r_s = -0.12$ $p > 0.05$	$r_s = -0.17$ $p > 0.05$	$r_s = -0.29$ $p > 0.05$
	C	$r_s = -0.16$ $p > 0.05$	$r_s = -0.12$ $p > 0.05$	$r_s = -0.06$ $p > 0.05$	$r_s = -0.16$ $p > 0.05$
	LPA	$r_s = 0.03$ $p > 0.05$	$r_s = -0.09$ $p > 0.05$	$r_s = -0.12$ $p > 0.05$	$r_s = -0.02$ $p > 0.05$
ICPNPD	BT	$r_s = -0.53$ $p < 0.05$	$r_s = -0.42$ $p < 0.05$	$r_s = -0.11$ $p > 0.05$	$r_s = -0.51$ $p < 0.05$
	EE	$r_s = -0.46$ $p > 0.05$	$r_s = -0.26$ $p > 0.05$	$r_s = -0.13$ $p > 0.05$	$r_s = -0.41$ $p < 0.05$
	C	$r_s = -0.19$ $p > 0.05$	$r_s = -0.45$ $p < 0.05$	$r_s = -0.07$ $p > 0.05$	$r_s = -0.23$ $p > 0.05$
	LPA	$r_s = -0.18$ $p > 0.05$	$r_s = -0.04$ $p > 0.05$	$r_s = -0.08$ $p > 0.05$	$r_s = -0.26$ $p > 0.05$

EE – Emotional Exhaustion, C – Cynicism, LPA – Lack of personal Accomplishment, TB – Total Burnout, ICPPD – Informal Caregivers of Patient with Psychiatric Disorder; ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder; r_s - Spearman's rank- order correlation, p – Significance level, DE/PS - Dealing with events / Problem Solving, DS - Dealing with stress symptoms, AP – Alternative perception, CAMI - Carers assessment of managing index (Coping strategies).

4.2.2.8 Correlation between the Burnout and the Stigma

Within the ICPPD we only found a positive and moderate correlation between the Avoidance dimension of the stigma and Total Burnout ($r_s = 0.434$, $p < 0.05$). The remained dimensions of Stigma and the total score did not show significant correlation with the Burnout levels. It should be noted that there were no differences in the levels of Stigma between ICPPD and ICPNPD ($U=733.0$, $p > 0.05$, $r=0.10$).

4.2.3 Linear regression models for Burnout in the overall sample

The model that best fits our sample to explain the Burnout levels without having into account the Caregiver type was formed by the predicting variables, stress, coping strategies, the existence of chronic illness and the smoking habits, this model 31% of the variation of Burnout. Stress and chronic illness show to have influence in the increase of Burnout and coping strategies showed the reverse. Regarding tobacco use, the model showed that smoking habit could be a sign of Burnout signaling (**Table 44**).

Table 44: Table which shows the components of the Linear Regression Models that better explain the variation of Burnout and its dimensions in the Overall sample.

Dependent Variable	Predictor Variable	B	SE of B	β	R ² of the Model	P
Total Burnout	Constant	2.21	0.92		0.31	< 0.05
	Stress	0.06	0.02	0.41		
	Coping strategies	- 0.02	0.01	- 0.30		
	Smoking habits	0.64	0.29	0.22		
	Chronic Disease	0.46	0.21	0.21		

LPA – Lack of Personal Accomplishment, B – Coefficient of the predictors, SE – Standard error, β – Standardized B, R² - Determination coefficient, p – Significance level.

4.2.4 Linear regression models for Burnout in the ICPPD

The linear regression model that best predicts Burnout had as predictors' variables, the Caregiver's chronic disease, and the coping strategies. This model only explained 23% of the Burnout variation. For Emotional Exhaustion, the best regression model had as predicting variables, the gender and chronic illness in the caregiver and also explained 23% of the variation in the emotional exhaustion (**Table 45**).

In the cynicism dimension, the best model explained only 12% of the cynicism variation and the predictor variable was stress. Moreover, lastly, the dimension Lack of personal accomplishment had as a predictors variables the sharing of the house with the patient and only managed to explain 14% of the variation in this dimension (**Table 45**).

Table 45: Table which shows the components of the Linear Regression Models that better explain the cause of Burnout and its dimensions in the group of ICPPD of our sample.

Dependent Variable	Predictor Variable	B	SE of B	β	R ² of the Model	P
Total Burnout	Constant	3.80	1.10		0.23	< 0.05
	Chronic disease	0.80	0.30	0.3		
	Coping Strategies	- 0.02	0.01	- 0.3		
Emotional Exhaustion	Constant	2.8	0.50		0.23	< 0.05
	Chronic disease	1.3	0.55	0.34		
	Gender	- 1.2	0.54	- 0.33		
Cynicism	Constant	- 0.85	0.91		0.12	< 0.05
	Stress	0.10	0.03	0.34		
LPA	Constant	2.40	0.38		0.14	< 0.05
	Home sharing	- 1.20	0.49	- 0.37		

LPA – Lack of Personal Accomplishment, B – Coefficient of the predictors, SE – Standard error, β – Standardized B, R² - Determination coefficient, p – Significance level.

4.2.5 Linear regression models for Burnout in the ICPNPD

For the ICPNPD, the model that best explains the Burnout is made up of Stress, caregiver’s gender, and readmissions, and it explains 47% of the Burnout variation. The model of emotional exhaustion only had a variable that is stress and only explains 16% of the variation in this dimension (**Table 46**).

The cynicism dimension had as predictive variables of the model that best fits, the stress, psychological help and hospitalization days. The best model for explaining the lack of personal fulfillment is formed by the variables stress, alcohol, and coping strategies and was able to explain 35% of the variation in personal achievement (**Table 46**).

Table 46: Table which shows the components of the Linear Regression Models that better explain the cause of Burnout and its dimensions in the group of ICPNPD of our sample.

Dependent Variable	Predictor Variable	B	SE of B	β	R ² of the Model	<i>p</i>
Total Burnout	Constant	- 0.47	0.38		0.47	< 0.05
	Stress	0.06	0.01	0.51		
	Gender	0.65	0.25	0.32		
	N.º of Readmissions	0.42	0.19	0.27		
Emotional Exhaustion	Constant	0.46	0.84		0.16	< 0.05
	Stress	0.10	0.03	0.40		
Cynicism	Constant	- 0.94	0.43		0.44	< 0.05
	Stress	0.05	0.02	0.42		
	Psychological Help	1.30	0.46	0.35		
	Days of Hospitalization	0.06	0.02	0.35		
LPA	Constant	1.81	1.23		0.35	< 0.05
	Stress	0.03	0.02	0.29		
	Alcohol	0.76	0.25	0.43		
	Coping Strategies	- 0.02	0.01	- 0.35		

LPA – Lack of Personal Accomplishment, B – Coefficient of the predictors, SE – Standard error, β – Standardized B, R² - Determination coefficient, *p* – Significance level.

CHAPTER V

Discussion and Conclusion

5 DISCUSSION AND CONCLUSION

5.1 Discussion

The sampling of this study was obtained through a nonprobabilistic sampling technique (convenience sampling) since the survey was only carried out in the city of Braga and only in two Hospitals (HB and CSBJ) that have internment services. This fact makes the generalization of study findings to the general population scientifically impossible, showing the need for a larger study to overcome this difficulty.

Our sample of informal caregivers consisted of 80 individuals, where half were ICPPD, and the other half were ICPNPD. Most caregivers were female (66.3%) as well as their patients (76.3%). The mean age of the caregivers was 49.8 years (SD = 15.9), and in the patients, it was 66.2 years (SD = 18.1).

The MBI-GS used in the study had a reasonable internal consistency with Cronbach's Alpha of 0.76 in the overall sample. The Emotional exhaustion dimension presented a Cronbach's Alfa of 0.80, the Cynicism dimension had Alpha of 0.62, and the Lack of personal accomplishment dimension had 0.87; these values were similar to those of others studies (De Oliveira Cruz Mendes, Claro, & Do Carmo Cruz Robazzi, 2014; Schutte et al., 2000)

The average of the Total Burnout in the overall sample of Informal caregivers was 1.66 (SD = 1.04), considered moderate if we used the cutoffs proposed by Kalimo (**Table 2**). This level of Burnout was lower than that observed in Portuguese physicians and nurses (Marôco et al., 2016) whose average was 3.00 (SD = 1.7), but in terms of classes of burnout, it is considered moderate as in our study. In another study conducted in Poland (Jaracz et al., 2017), the mean values of Burnout in nurses (mean = 1.17, SD = 0.26) and public servants (mean = 1.24, SD = 0.36) were lower than those we found. As it can be seen, our results values were between the two studies, which allow us to consider them reliable.

In our overall sample, we had more caregivers with moderate Burnout (45%) than with Severe Burnout (9%). Studies in health professionals showed that only 21.6% of the professionals had moderate Burnout and about 47.8% had Severe Burnout (Marôco et al., 2016). We can consider that the Formal caregivers have more risk to present Burnout than the Informal caregivers, maybe because the formal caregivers have no familiar linkage with the patient.

The linear regression model for explaining the variation of Burnout score in the overall sample had as predictors variables, the caregiver's stress which explained 17% of the Burnout variation, coping strategies (9% of the variation), smoking habits (5% of the variation) and chronic disease (4% of the variation). Although more studies are needed to find other predictors, this model shows the need for more psychosocial support for caregivers to improve the effectiveness of their coping strategies to reduce the burden of stress and also shows the need for more social attention with patients whose caregivers have a chronic disease. We did not find a relationship between burnout and the amount of time as a caregiver in the overall sample. Among medical doctors and nurses, the national study on Burnout showed that as much the time as employee increase the levels of Burnout decrease (Marôco et al., 2016).

In the comparison of the medians of the Burnout score between the ICPPD (median = 1.74) and the ICPNPD (median = 1.22), the differences were statistically significant ($U = 561.5$, $p < 0.05$, $r = -0.26$), the ICPPD with levels of moderate Burnout and ICPNPD with low levels. The mean of the Burnout score in the ICPPD (mean = 1.91, SD = 1.12) was closer to that of health professionals (mean = 3.0, SD = 1.7) (Marôco et al., 2016) than that of the ICPNPD (mean = 1.41, SD = 0.91).

The IC of patients with schizophrenia had more Burnout than the IC of patients with depression, but the difference wasn't statistically significant ($U = 152$, $p > 0.05$, $r = 0.16$). The burnout levels among ICs of patients with the Non-Psychiatric Disorder were not different from those observed in ICs of patients with depression but were significantly lower than those found in ICs of patients with schizophrenia, which means the ICs of patients with schizophrenia need more support. The lack of insight, as well as the refusal to recognize the illness by the patients with schizophrenia, may have exacerbated the Burnout in their caregivers.

Our linear regression models showed that the predictors' variables of Burnout in the ICPPD were the chronic disease of the caregiver ($B = 0.80$) and the efficiency of the coping strategies ($B = -0.02$), but these two predictive variables only explained 23% of the Burnout variation in this group. A study published in Turkey showed a similarity with our findings, in which the caregiver's burnout of patients with schizophrenia was correlated with the lack of social support (Kokurcan, Özpolat, & Göğüş, 2015). The lack of this support can make the caregiver to be deprived of strategies to deal with stressful situations. Other studies show that caregiver psychological education should focus on helping relatives

cope with stressful situations that hinder the caregiver-patient relationship in order to help the caregiver deals better with the patient's behavior (Cuijpers & Stam, 2000).

The socio-demographic variables of the caregiver (gender, age, and marital status) showed no significant influence on the Burnout level of ICPPD and ICPNPD. These findings were also verified in studies of Burnout in caregivers of patients with schizophrenia in Turkey (Demirbas, Tugba, & Kizil, 2017) and studies of Burnout in Portugal (Marôco et al., 2016). The tendency of Burnout increase was verified in women, singles, and people with less than 35 years or over 65 years, but it wasn't statistically significant.

The level of education, occupation, and sharing of residence with the patient also did not show significant influence on the levels of Burnout of the two groups of caregivers. However, the degree of kinship had influence in the Burnout of the ICPPD but not in the ICPNPD. These findings resemble that of other studies on mental health (Demirbas et al., 2017), except that the degree of kinship also influences ICPPD burnout, which was a new finding where parents of the patients appear to be at higher levels of Burnout. We want to believe that this fact could have been affected by the size of our sample which was reduced in some degrees of kinship.

The amount of time the family member spent daily with his patient (working hours) had no influence on the burnout of the two groups of caregivers. In the study in health professionals, other researchers also obtained the same results (Marôco et al., 2016). The contradictory finding with the Study in health professionals was that the long time as a health professional led to a decrease in burnout (Marôco et al., 2016) but in ICPPD, those who were more than ten years as caregivers had higher levels of burnout compared to those who had one to two years as caregivers, possibly because of the fatigue. However, this was not the case with the ICPNPD.

The request for psychiatric and psychological help by the caregivers in our study did not show to have been influenced by the caregivers' Burnout levels in both ICPPD and ICPNPD. The percentage of caregivers who sought psychiatric or psychological help was small, we believe that most caregivers with stress initially seek the help of the family doctor than a specialist consultation, which reduced the number of ICs who sought the specialist consultation.

In the evaluation of Burnout dimensions, we found that there were no significant differences between ICPPD and ICPNPD in terms of Burnout dimensions medians, except in one dimension, the Lack of personal accomplishment. Although the level of Lack of personal accomplishment was very small (Median = 1.0) the ICPPD showed relatively high levels than the ICPNPD ($U = 283.0$, $p < 0.05$, $r = 0.80$). The Nurses in a study conducted in some states of Nigeria showed that the mean of the Lack of personal accomplishment was 0.9 (SD = 1.1) and in our overall sample was 1.0 (SD = 1.4), showing no difference between formal and informal caregivers (Gandi, Wai, Karick, & Dagona, 2011). We believe that this small lack of personal accomplishment, although they were in Burnout, is due to compensation with the other spheres of the social life, but studies are needed to prove.

A study carried out in health professionals in Italy (Portoghese, Galletta, Coppola, Finco, & Campagna, 2014) on the dimensions of emotional exhaustion and cynicism showed that the mean for emotional exhaustion (mean = 2.69; SD = 1.50) was very similar with that we found in our overall sample (mean = 2.65; SD = 1.79) but for the cynicism dimension, our mean (mean = 0.96, SD = 1.16) was lower than that of health professionals (mean = 1.76; SD = 1.35). The reduced cynicism in informal caregivers in our opinion is because these caregivers are the direct family of the patient compared to health professionals whose there is not a strong affective bond with the patient.

The socio-demographic and clinical variables of the ICPPD that significantly influenced the Emotional exhaustion dimension were gender, the number of years as a caregiver and the chronic illness of the caregiver. The majority of caregivers who request for psychological help had high levels of emotional exhaustion compared to those who didn't request. For the dimension Personal realization, only the sharing of residence significantly influenced personal achievement, where those who shared the home with the patient had better personal fulfillment.

Still, within the ICPPD, the cynicism dimension was influenced by the variables degree of kinship and gender, where the parents of the patient and the female caregivers had relatively higher levels of cynicism. Early studies show that the degree of kinship does not influence the burnout (Demirbas et al., 2017), We believe that the fact that the number of caregivers who were fathers and mothers was greater compared to the other degrees of kinship has influenced the result, it is necessary to do the same study with a larger sample.

Regarding the effect of socio-demographic variables on the burnout dimensions of the ICPNPD, only the variable Age of caregiver showed a significant impact on the Lack of personal accomplishment dimension, in which the young people stood out with increased levels. This finding was also found in a Burnout study in physicians (Khanna & Khanna, 2013). This lack of personal fulfillment is possible due to lack of experience and stability in young professionals (Khanna & Khanna, 2013).

The patient's dependence on the basic activities of daily living showed no influence on the levels of Burnout in the both IC groups. However, the dependence on the instrumental activities of daily living significantly affected the Burnout of ICPPD. Those patients who had a moderate to severe dependency caused more burnout to their caregivers than those who had low, possibly due to the increased time of support and greater fear and concern about his future and the future of his patient, since Psychiatric Disorder is incurable (Custódio, 2011).

In the evaluation of stress, although the stress in the ICPPD was slightly elevated than that observed in the ICPNPD the differences found were not statistically significant. This result contradicts previous studies that showed a significant difference between the two groups, where the ICPPD's stress was up to three times higher than ICPNPD's stress (Anand, Dhikav, Sachdeva, & Mishra, 2016). This difference between the two studies may have to do with Psychiatric Disorder chosen to be part of the survey, we chose Schizophrenia and Depression, and the other study adopted Alzheimer disease and the Mild cognitive impairment (Anand et al., 2016). The latter study also found a correlation between stress and patient dependence for daily life activities, for our study there was no significant correlation between them. It should be noted that the major part of the patients with organic pathology in this study was elderly with several medical pathologies associated compared to the patients with Psychiatric Disorder, which may have influenced for greater similarity in stress levels.

In the evaluation of ICPPD's stress, we found that the female ICs had more stress than male ICs; this corroborates with the findings of the previous studies (Silva & Gomes, 2009). This increased stress in female subjects is seen to be related to the fact that the women are more sociable, sensitive, with overwork and familiar problems and feeling of lack of power and recognition than men (Ana Filipa Ribeiro Sapata, 2012; Khanna & Khanna, 2013; Silva & Gomes, 2009). Within the ICPNPD, smokers presented high levels of stress, not being the cigar a cause of stress, but as a factor chosen by the caregiver to relieve stress.

The socio-demographic and clinical variables of the caregiver which presented a statistically significant relationship with the coping strategies chosen by the IC were: age, marital status, education, alcoholic, and smoking habits. The older caregivers, the single caregivers, the caregivers with more education or with alcoholic and smoking habits had the perception of better efficiency in the coping strategies chosen. Nurses' studies in Portugal point only to age, gender and the relationship with the institution as factors influencing coping strategies (Ana Filipa Ribeiro Sapata, 2012).

The stigma levels between ICPPD and ICPNPD were similar and low. For both ICPPD and ICPNPD, the stereotypes with a relatively high score of stigma were Coercion and Pity. The coercion had to do with the fact that some people with Psychiatric Disorder sometimes do not have any critical judgment of their disease what makes their family force them to treat themselves. The two groups showed no fear and did not consider the person with Psychiatric Disorder as dangerous, being able to help without blaming them for their illness, which was supported by the low levels of stigma related to helping, avoidance and responsibility dimensions.

A previous study on stigma in relatives of patients with Psychiatric Disorder, carried out at Hospital São João had the same results as ours, where the Pity and Coercion stereotypes were highlighted among family members as those that most influence the total stigma score (Sousa et al., 2012).

Regarding the study of correlations between Burnout and explanatory variables, gender, the number of readmissions, the number of days of hospitalization and stigma had no significant association with Burnout in the overall sample. Previous studies also showed no correlation of Burnout with gender (Marôco et al., 2016), but others had opposite results (Khanna & Khanna, 2013). However, as another Portuguese study had the same result, we want to believe that the lack of differences in Burnout between the genders is real.

Among ICPPD, only two variables correlated with Burnout, the age of the patient with negative correlation and the patient's dependence on instrumental activities with positive correlation. The national study in health professionals found that poor working conditions were directly related to Burnout (Marôco et al., 2016). The poor working conditions of the formal caregiver can be compared in the informal caregiver to the greater dependence of the patient for instrumental activities, requiring the caregiver to remember things for the patient, like taking medication and self-care.

For ICPNPD, the variables that had a significant correlation with Burnout were stress and coping strategies. Usually, the hospitalization of the patient with an organic disease has a lot to do with the risk of the patient losing his life, a situation that is difficult for the IC, becoming disoriented and with high levels of stress. The fact that the interview was done at a time of such distress, it may have influenced more to the burnout of caregivers of patients with organic disease. The disorientation often leads to the choice of wrong coping strategies hence their negative impact on the burnout of these caregivers. The effects of stress on Burnout have also been demonstrated in public servants and nurses (Jaracz et al., 2017).

The linear regression model that best predicts Burnout in ICPPD had as predictors' variables, the Caregiver's chronic disease, and the coping strategies. This model only explained 23% of the Burnout variation. This model shows that chronic illness increases the burden on the caregiver which in turn leads to Burnout. So it is needed more attention for the patient with Psychiatric Disorder particularly those who have Caregivers with a chronic disease. The inefficiency of the coping strategies demonstrated by this model shows that ICPPD needs more psychosocial support than ICPNPD to improve their coping skills.

For the ICPNPD, the model that best explains the Burnout is made up of caregiver's stress, caregiver's gender, and the number of patient's readmissions, and it explains 47% of the Burnout variation. This model demonstrates that, although the stress of the ICPNPD is similar to ICPPD stress, it has more impact on the Burnout development in the ICPNPD. In this model, we can also conclude that female ICPNPD needs more help than males and that the high number of readmissions increases the psychological distress of the caregivers, possibly because they have to give up part of their life to care the patient.

5.2 Conclusion

Burnout is a psychological syndrome characterized mainly by the presence of emotional exhaustion, attitudes of depersonalization or cynicism and feelings of lack of personal fulfillment. It may be present in professionals who deal with Clients in distress as well as in other professions including individuals who have the social or voluntary task of caring for others.

The study consisted basically in the characterization and identification of some factors that can influence Burnout in Informal caregivers of patients with Psychiatric Disorder (ICPPD) using as a means of comparison the Informal Caregivers of Patients with Non-Psychiatric Disorder (ICPNPD). Of note some limitations are to be considered including: (i) the subjectivity of the questions of the different inventories and limited number of answers; (ii) the answers to the questionnaires depended on the sincerity of the participant; (iii) some questionnaires had an exaggerated number of questions, showing a need of abbreviation of some instruments in the future surveys; (iv) The convenience sampling technique.

Results indicate that ICPPD had significantly higher levels of Burnout in comparison with ICPNPD, being moderate in ICPPD (mean = 1.91, SD = 1.12) and low in ICPNPD (mean = 1.41, SD = 0.91). The percentage of caregivers with Burnout was higher in ICPPD (65%) compared to ICPNPD (42%).

The levels of stress, levels of perceived effectiveness of the coping strategies, and the levels of Psychiatric Disorder stigma were not significantly different in both groups. However, stress had a significant impact on the Burnout regression model in ICPNPD compared to ICPPD. The efficiency of coping strategies had more impact on ICPPD compared to ICPNPD and the Psychiatric Disorder stigma perceived by the ICPPD had no effect on their Burnout levels.

Regarding the socio-demographic and clinical variables of the patient and caregiver, the caregiver's gender and the number of readmissions of the patient significantly influenced Burnout in ICPNPD, where the female gender and the high number of readmissions were correlated with high levels of Burnout, not with a significant effect on ICPPD. The degree of dependence of the patient on instrumental activities of daily living, the age of the patient and the presence of chronic disease in the caregiver or the long period as caregiver had a significant effect on ICPPD Burnout compared to ICPNPD,

where caregivers with chronic illness and those who care for a patient with a high level of dependence or who care for younger patients had more Burnout experience.

The association of the lack of efficiency of coping strategies adopted by the caregiver with the high levels of Burnout demonstrates the need to provide caregivers with the necessary tools to deal with the difficulties in their task of caregivers, particularly female caregivers, those who have a chronic Disease, those whose patients have elevated number of hospitalizations and caregivers with high levels of stress.

The same attention to formal caregivers regarding Burnout should be the same for family members and other informal caregivers. Knowing the state of physical and mental health of the caregiver is of paramount importance in patient recovery and prevention of the consequences of burnout in the caregiver. Variables such as gender, period as a caregiver, coping strategies, stress and chronic illness of the informal caregiver as well as the number of readmissions of the patient and the degree of dependence of the patient can be used as a means of Burnout screening in the Informal caregivers.

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Supplementary Information

Appendix and Annexes

Appendix – I

Table 47: Evaluation of the normality of dependent and predictive variables using the Shapiro-Wilk test.

Variables	ICPPD			ICPNPD		
	Shapiro-Wilk's test			Shapiro-Wilk's test		
	Statistic	df	<i>p</i>	Statistic	df	<i>p</i>
Subject's age	0.948	38	0.077	0.979	40	0.667
Age of patient	0.964	38	0.251	0.754	40	0.000
Number of readmission	0.627	38	0.000	0.746	40	0.000
Number of days of hospitalization	0.583	38	0.000	0.689	40	0.000
Barthel index	0.371	38	0.000	0.878	40	0.000
Lawton index	0.746	38	0.000	0.880	40	0.001
Emotional Exhaustion Dimension	0.939	38	0.040	0.959	40	0.154
Cynicism Dimension	0.828	38	0.000	0.737	40	0.000
Lack of Personal Efficiency	0.854	38	0.000	0.516	40	0.000
Burnout score	0.938	38	0.037	0.946	40	0.057
Coping strategies Score	0.983	38	0.827	0.988	40	0.949
Level of Psychiatric Disorder Stigma	0.911	38	0.005	0.901	40	0.002
Perceived Stress Scale	0.954	38	0.125	0.985	40	0.868

ICPPD – Informal Caregivers of Patient with Psychiatric Disorder, ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder, df - Degrees of freedom, *p* – Significance level.

Appendix – II

Table 48: Evaluation of the normality of dependent and predictive variables using the Shapiro-Wilk test.

Variables		ICPPD			ICPNPD		
		Shapiro-Wilk			Shapiro-Wilk		
		Statistic	df	<i>p</i>	Statistic	df	<i>p</i>
Subject's age	Female	.908	18	.079	.976	34	.635
	Male	.942	20	.260	.977	6	.933
Age of patient	Female	.965	18	.700	.754	34	.000
	Male	.921	20	.104	.766	6	.028
Number of readmission	Female	.539	18	.000	.769	34	.000
	Male	.825	20	.002	.831	6	.111
Number of days of hospitalization	Female	.637	18	.000	.666	34	.000
	Male	.618	20	.000	.891	6	.322
Barthel index	Female	.253	18	.000	.873	34	.001
	Male	.458	20	.000	.840	6	.130
Lawton index	Female	.791	18	.001	.868	34	.001
	Male	.713	20	.000	.936	6	.630
Emotional Exhaustion Dimension	Female	.929	18	.183	.956	34	.190
	Male	.898	20	.038	.885	6	.295
Cynicism Dimension	Female	.847	18	.007	.758	34	.000
	Male	.815	20	.001	.908	6	.421
Lack of Personal Efficiency	Female	.835	18	.005	.476	34	.000
	Male	.877	20	.015	.610	6	.001
Burnout score	Female	.847	18	.008	.914	34	.011
	Male	.985	20	.979	.858	6	.184
Coping strategies Score	Female	.981	18	.958	.974	34	.587
	Male	.985	20	.984	.770	6	.031
Level of Psychiatric Disorder Stigma	Female	.819	18	.003	.894	34	.003
	Male	.962	20	.587	.901	6	.381
Perceived Stress Scale	Female	.942	18	.318	.969	34	.446
	Male	.948	20	.331	.732	6	.013

ICPPD – Informal Caregivers of Patient with Psychiatric Disorder, ICPNPD – Informal Caregivers of Patient with Non-Psychiatric Disorder, df - Degrees of freedom, *p* – Significance level.

Annex – I

Information to the participant and Informed consent form

INVESTIGADOR

TERMO DE CONSENTIMENTO INFORMADO

CARACTERIZAÇÃO DO BURNOUT DOS CUIDADORES DE PACIENTES COM DOENÇA PSIQUIÁTRICA

Este projeto de investigação tem como objetivo avaliar o nível do *Burnout* (cansaço e/ou possível desgaste psicológico e físico) dos cuidadores informais, isto é, familiares e outros responsáveis não remuneráveis de doentes com transtornos psiquiátrico, utilizando como controlo cuidadores informais de doentes com doença crónica não-psiquiátrica.

Serão correlacionados dados de *Burnout* e os seguintes fatores em cuidadores informais: o estresse, o estigma, as estratégias de *coping* (de “lidar com as dificuldades”) e os dados sociodemográficos. Para tal está previsto o preenchimento de questionários sobre: dados gerais sociodemográficos e clínicos, hábitos tabágicos e de consumo de álcool; estresse; estado de esgotamento físico e psicológico, nível de estigma em relação as pessoas que sofrem de doença psiquiátrica ou não psiquiátrica e sobre a maneira de lidar com as dificuldades de ser cuidador.

Não estão associados quaisquer efeitos secundários à sua participação neste estudo, podendo, no entanto, ter algum nível de cansaço associado a responder a múltiplos questionários. A sua participação terá uma duração de cerca de uma hora de tempo. No estudo não será feito nenhuma colheita de sangue, ou de qualquer fluido orgânico, ou exame clínico e/ou de diagnóstico associado.

Eu, abaixo-assinado fui informado sobre o Estudo de Investigação acima mencionado.

Foi-me garantido que todos os dados relativos à identificação dos participantes neste estudo são confidenciais e que será mantido o anonimato.

Foi-me explicado em que consistem e quais os seus possíveis efeitos.

Sei que posso recusar-me a participar ou interromper a qualquer momento a participação no estudo, sem nenhum tipo de penalização por este facto. Para tal posso contactar o hospital na qual o/a meu/minha doente é seguido/a ou posso contactar o investigador Rogério João Mulumba através dos números 960442790/253139385 e email pg31200@alunos.uminho.pt ou posso contactar a supervisora da investigação Nadine Santos através do email nsantos@alunos.uminho.pt.

Compreendi a informação que me foi dada, tive oportunidade de fazer perguntas e as minhas dúvidas foram esclarecidas.

Aceito participar de livre vontade no estudo acima mencionado e sei que posso não participar e/ou desistir a qualquer momento sem qualquer repercussão e/ou prejuízo associado na minha relação, e/ou do doente, com a equipa de clínica e/ou de investigação.

INVESTIGADOR

Também autorizo a divulgação dos resultados obtidos no meio científico, desde que garantido o anonimato.

Nome do Participante no estudo

Data

Assinatura

__/__/__

Nome do Investigador Responsável

Data

Assinatura

__/__/__

O estudo foi devidamente submetido para aprovação das Comissões de Ética responsáveis, recebendo a devida aprovação.

Este documento consiste de duas páginas e é feito em duplicado, uma cópia para o investigador e uma cópia para quem consente.

Annex – II

Socio-demographic inventory

Questionário N.º	1
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Data:			
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Código do Participante	
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DADOS SOCIO-DEMOGRÁFICOS E CLÍNICOS DO CUIDADOR E SEU DOENTE

DADOS SOCIO-DEMOGRÁFICOS E CLÍNICOS DO CUIDADOR

No inquérito abaixo são apresentadas algumas características sociais e demográficas, bem como alguns hábitos e dados clínicos dos cuidadores. Coloque um **X** na característica com que mais se identifica. Caso não esteja representada a sua opção, preencha no espaço em branco descrito como outro/a.

1. IDADE (do/a cuidador/a)

	Anos
--	------

2. SEXO (do/a cuidador/a)

 Masculino Feminino

3. ESTADO CIVIL (do/a cuidador/a)

 Solteiro/a Casado/a Vive com um/a companheiro/a em união de facto Divorciado/a Separado/a mas legalmente casado/a Viúvo/a

Questionário N.º	1
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Data:			
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Código do Participante	
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4. QUAL É O NÍVEL DE ENSINO MAIS ELEVADO QUE COMPLETOU?

- Nenhum
- Ensino básico 1º ciclo (atual 4º ano/antiga instrução primária/4ª classe)
- Ensino básico 2º ciclo (atual 6º ano/antigo ciclo preparatório)
- Ensino básico 3º ciclo (atual 9º ano/antigo 5º liceal)
- Ensino secundário (atual 12º ano/antigo 7º liceal/ano propedêutico)
- Ensino pós-secundário (Cursos de especialização tecnológica, nível IV)
- Bacharelato (inclui antigos cursos médios)
- Licenciatura
- Mestre
- Doutoramento

5. SITUAÇÃO OCUPACIONAL (do/a cuidador/a)

- Trabalha por conta de outrem
- Trabalha por conta própria
- Reformado/a
- É incapacitado perante ao trabalho
- Desempregado/a
- Estudante
- Outra _____

Questionário N.º **1**

Data:

Código do Participante

6. GRAU DE PARENTESCO DO/A CUIDADOR/A COM RELAÇÃO AO DOENTE

- Pai/mãe
- Cônjuge
- Companheiro/a
- Filho/a
- Irmão/o
- Neto/a
- Sobrinho/a
- Tio/a
- Outro _____

7. LOCALIDADE (do/a cuidador/a)

Habita com o doente?

Não

Sim

Se sim, A tempo inteiro Parcialmente

8. Atualmente cuida de quantas pessoas doentes?

Uma

Mais de uma

Questionário N.º	1
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Data:			
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Código do Participante	
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9. Durante o ano cuida desta pessoa:

Todos os dias

Apenas durante 6 meses

Mais que 6 meses

Menos que 6 meses

Ocasionalmente quando esta doente

De outra forma (especificar) _____

10. Quantas horas por dia gasta, aproximadamente, a cuidar desta pessoa?

Menos de 1 hora

Entre 1 a 2 horas

De 2 a 3 horas

De 3 a 5 horas

Mais de 5 horas

11. Há quanto tempo cuida desta pessoa?

Entre 1 a 2 anos

Entre 3 a 5 anos

Entre 6 a 10 anos

Mais de 10 anos

Questionário N.º	1
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Data:			
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Código do Participante	
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12. Das pessoas que vivem habitualmente consigo, alguém o ajuda na prestação de cuidados?

Sim

Não

13. Recebe apoio de alguma instituição?

Sim

Não

HISTÓRIA MÉDICA DO/A CUIDADOR/A

Pedimos-lhe que responda agora a algumas perguntas sobre a **SUA** história de saúde e de acompanhamento médico, ou seja, a história médica do cuidador/a.

1. Alguma vez teve uma consulta de psiquiatria?

Sim

Não

2. Alguma vez teve uma consulta de psicologia?

Sim

Não

3. Tem alguma doença crónica?

Sim Se sim, qual? _____

Não

Questionário N.º	1
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Data:			
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Código do Participante	
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4. Alguma vez tomou psico-farmacos?

Sim Se sim, qual? _____

Não

5. Hábitos tabágicos e alcoólicos

a. É fumador? SIM NÃO

Se SIM, quantos cigarros fuma por dia

Menos que 5 (ou somente em ocasiões sociais)

5-9

10-14

15-24

Mais de 25

Outro produto tabágico. Qual? _____ Quanto(s) por dia? _____

b. Consome bebidas alcoólicas? SIM NÃO

Se SIM, com que frequência?

Algumas vezes por ano e/ou somente em ocasiões sociais

Uma vez por mês

Algumas vezes por mês

Uma vez por semana

Algumas vezes por semana

Todos os dias

Questionário N.º	1
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Data:			
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Código do Participante	
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-- A SER PREENCHIDO PELO INVESTIGADOR --

DADOS SOCIO-DEMOGRÁFICOS E CLÍNICOS DO/A DOENTE

1. IDADE (do/a doente)

Anos

2. SEXO (do/a doente)

Masculino

Feminino

3. ESTADO CIVIL (do/a doente)

Solteiro/a

Casado/a

Divorciado/a

Divorciado/a com companheiro/a

Viúvo/a

União de facto

Companheiro/a

Separado/a

Outro/a

Questionário N.º	1
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Data:			
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Código do Participante	
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4. HABILITAÇÕES LITERÁRIAS (do/a doente)

- Analfabeto/a
- Sabe ler e escrever
- Primário Ciclo/Instrução primária
- Segundo Ciclo/9º Ano/ou antiga 5ª Classe
- Terceiro Ciclo/ 10º Ano ao 11º Ano / ou 7º Ano complementar
- 12º Ano (Completo ensino secundário)
- Curso profissional técnico
- Curso superior
- Outro (Ex: Doutoramento) _____

5. SITUAÇÃO OCUPACIONAL (do/a doente)

- Trabalha por conta de outrem
- Trabalha por conta própria
- Pensão
- Invalidez
- Estudante
- Outra

Questionário N.º **1**

Data:

Código do Participante

6. GRAU DE PARENTESCO DO DOENTE COM RELAÇÃO AO CUIDADOR

- Pai/mãe
 Cônjuge
 Companheiro/a
 Filho/a
 Irmã/o
 Neto/a
 Sobrinho/a
 Tio
 Outro _____

LOCALIDADE

Habita com o doente?

Sim

Não

Se sim, A tempo inteiro Parcialmente

Questionário N.º	1
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Data:			
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Código do Participante	
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HISTÓRIA MÉDICA DO/A DOENTE

Após o consentimento da Direcção do Hospital, foram retiradas estas informações do processo do doente correspondente ao cuidador entrevistado.

1. Diagnóstico principal?

Esquizofrenia

Depressão

Doença de Chron

2. Número de readmissões/internamentos no Hospital onde estão a ser obtidos os dados?

vezes, desde o ano .

Número médio anual de dias de Internamento:

3. Hábitos tabágicos e alcoólicos

a) É fumador? SIM NÃO

Se SIM, quantos cigarros fuma por dia

Menos que 5 (ou somente em ocasiões sociais)

5-9

10-14

15-24

Mais de 25

Outro produto tabágico. Qual _____ . Quanto(s) por dia? _____

Annex – III

Barthel Index

Questionário N.º	1
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Data:			
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Código do Participante	
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Índice de Barthel, versão abreviada (Mahoney & Barthel, 1965; Sequeira, 2007)

Actividade básica de vida diária do doente (ABVD)

Leia atentamente cada uma das afirmações, e indique de que modo se aplicam ao seu doente, colocando o sinal X no espaço que melhor corresponde à sua opinião.

Item	ABVD	Cotação	Item	ABVD	Cotação
Alimentação	Independente	10	Vestir	Independente	10
	Necessita de ajuda	5		Necessita de ajuda	5
	Dependente	0		Dependente	0
Banho	Independente	5	Higiene corporal	Independente	5
	Dependente	0		Dependente	0
Controlo intestinal	Independente	10	Controlo vesical	Independente	10
	Incontinência ocasional involuntária	5		Incontinência urinária ocasional	5
	Incontinência fecal	0		Incontinência ou algaliado	0
Uso da casa de banho	Independente	10	Subir escadas	Independente	10
	Necessita de ajuda	5		Necessita de ajuda	5
	Dependente	0		Dependente	0
Transferência cadeira-cama	Independente	15	Deambulação	Independente	15
	Necessita de ajuda mínima	10		Necessita de ajuda	10
	Necessita de grande ajuda	5		Independente com cadeira de rodas	5
	Dependente	0		Dependente	0

Annex – IV

Barthel Lawton

Questionário N.º	1
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Data:			
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Código do Participante	
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Índice de Lawton, Versão abreviada (Lawton & Brody, 1969; Sequeira, 2007)

Actividades instrumentais de vida diária (AIVD)

Leia atentamente cada uma das afirmações, e indique de que modo se aplicam ao seu doente, colocando X no espaço que melhor corresponde a sua opinião.

Item	AIVD	Cotação	Item	AIVD	Cotação
Cuidar da casa	Sem ajuda	1	Uso de telefone	Sem dificuldade	1
	Tudo menos trabalho pesado	2		Só para números familiares	2
	Tarefas leves	3		Necessita de ajuda	3
	Ajuda para todas as tarefas	4		Incapaz de usar	4
	Incapaz de qualquer tarefa	5			
Lavar roupa	Lava a sua roupa	1	Uso de transporte	Viaja em transporte ou conduz	1
	Só lava peças pequenas	2		Só anda de táxi	2
	Incapaz	3		Necessita de acompanhamento	3
				Incapaz	4
Preparar a comida	Planeia, prepara e serve sem ajuda	1	Uso do dinheiro	Paga as contas, vai ao banco, etc.	1
	Prepara se lhe derem os ingredientes	2		Só pequenas quantidades de dinheiro	2
	Prepara pratos pré-cozinhados	3		Incapaz de utilizar o dinheiro	3
	Incapaz de preparar qualquer refeição	4			
Ir às compras	Faz as compras sem ajuda	1	Uso de medicamento	Responsável pela sua medicação	
	Só faz pequenas compras	2		Necessita que lhe preparem a medicação	
	Faz as compras acompanhado	3		Incapaz	
	Incapaz	4			

Annex – V

Maslach Burnout Inventory

Questionário N.º	2
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Data:			
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Código do Participante	
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ESCALA DE BURNOUT DE MASLACH - GS
(Shaufeli, Leiter, Maslach & Jackson, 1996; Nunes, 1999)

Em seguida existem afirmações sobre sentimentos relacionados com o trabalho. Leia cada afirmação cuidadosamente e decida o que sente sobre o seu trabalho/tarefa de cuidador. Se nunca apresentou esse sentimento coloque um círculo no zero (0). Se já teve indique a frequência que melhor descreve (de 1 a 6).

1. No meu trabalho (de cuidador) sinto-me exausto/a emocionalmente.

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

2. Sinto-me usado/a ao fim de um dia de trabalho (como cuidador).

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

3. Sinto-me cansado/a quando me levanto de manhã e tenho que trabalhar (como cuidador).

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

4. Trabalhar (como cuidador) todo o dia causa-me estresse.

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

Questionário N.º	2
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Data:			
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Código do Participante	
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5. Eu consigo resolver eficazmente os problemas que aparecem no meu trabalho (de cuidador).

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

6. O meu trabalho (de cuidador) deixa-me exausto.

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

7. Eu sinto que estou a contribuir eficazmente para os objetivos do meu trabalho (de cuidador).

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

8. Eu estou a ficar menos interessado no meu trabalho (de cuidador) desde que comecei a trabalhar como cuidador.

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

9. Eu estou a ficar com menos entusiasmo sobre o meu trabalho (de cuidador).

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

Questionário N.º	2
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Data:			
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Código do Participante	
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10. Na minha opinião, eu sou bom naquilo que faço.

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

11. Eu sinto-me alegre quando consigo atingir algo no meu trabalho (de cuidador).

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

12. No meu trabalho (de cuidador), eu tenho conseguido realizar muitas coisas que valem a pena.

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

13. Eu só quero fazer o meu trabalho (de cuidador) e que não me incomodem.

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

14. Eu estou a ficar mais cético (incrédulo) se o meu trabalho (de cuidador) contribui para alguma coisa.

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

Questionário N.º	2
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Data:			
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Código do Participante	
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15. Eu duvido do significado do meu trabalho (de cuidador).

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

16. No meu trabalho (de cuidador), eu sinto-me confiante de que sou eficaz em ter as coisas feitas.

- 0 - Nunca
- 1 - Algumas vezes por ano
- 2 - Uma vez por mês
- 3 - Algumas vezes por mês
- 4 - Uma vez por semana
- 5 - Algumas vezes por semana
- 6 - Todos os dias

Annex – VI

Carers Assessment of Managing Index

Questionário N.º	3
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Data:			
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Código do Participante	
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FORMAS DO PRESTADOR DE CUIDADOS ENFRENTAR AS DIFICULDADES (Brito, 2002; Sequeira 2007; 2010)

Índice para avaliação das maneiras como o prestador de cuidados enfrenta as dificuldades (CAMI). O CAMI é uma lista de 38 afirmações, feitas por pessoas que prestam cuidados, acerca das maneiras como habitualmente enfrentam as suas dificuldades. Leia atentamente cada uma das afirmações, e indique de que modo se aplicam ao seu caso, colocando o sinal X no espaço que melhor corresponder à sua opinião. A partir das suas respostas poderão ser encontradas formas de apoio à pessoa que presta cuidados.

N.º	Uma das maneiras de enfrentar as dificuldades que tenho, ao cuidar desta pessoa, é:	Não procedo desta forma	Faço assim e acho que:		
			Não dá resultado	Dá algum resultado	Dá bastante bom resultado
1	Estabelecer um programa regular de tarefas, e procurar cumpri-lo				
2	Descarregar a tensão, falando alto, gritando, ou coisa semelhante				
3	Falar dos meus problemas com alguém em quem confio				
4	Reservar algum tempo livre para mim próprio				
5	Planear com antecedência e assim estar preparado para as coisas que possam acontecer				
6	Ver o lado cómico da situação				
7	Pensar que há sempre quem esteja pior do que eu				
8	Cerrar os dentes e continuar				
9	Recordar todos os bons momentos que passei com a pessoa de quem cuido				
10	Procurar obter toda a informação possível acerca do problema				

Questionário N.º 3

Data:

Código do Participante

N.º	Uma das maneiras de enfrentar as dificuldades que tenho, ao cuidar desta pessoa, é:	Não procedo desta forma	Faço assim e acho que:		
			Não dá resultado	Dá algum resultado	Dá bastante bom resultado
11	Pensar que a pessoa de quem cuido não tem culpa da situação em que está				
12	Viver um dia de cada vez				
13	Conseguir que a família me dê toda a ajuda prática que puder				
14	Manter a pessoa de quem cuido tão activa quanto possível				
15	Modificar as condições da casa de modo a facilitar as coisas o mais possível				
16	Pensar que a situação está agora melhor do que antes				
17	Obter toda a ajuda possível dos serviços de saúde e dos serviços sociais				
18	Pensar no problema e encontrar uma forma de lhe dar solução				
19	Chorar um bocado				
20	Aceitar a situação tal como ela é				
21	Arranjar maneira de não pensar nas coisas, lendo, vendo televisão ou algo semelhante				
22	Fazer como se o problema não existisse e esperar que ele passe				
23	Tomar medidas para evitar que os problemas surjam				
24	Agarrar-me a fortes crenças pessoais ou religiosas				
25	Acreditar em mim próprio e na minha capacidade para lidar com a situação				

Questionário N.º 3

Data: _____

Código do Participante _____

N.º	Uma das maneiras de enfrentar as dificuldades que tenho, ao cuidar desta pessoa, é:	Não procedo desta forma	Faço assim e acho que:		
			Não dá resultado	Dá algum resultado	Dá bastante bom resultado
26	Esquecer os problemas por momentos, deixando divagar o pensamento				
27	Manter dominados os meus sentimentos e emoções				
28	Tentar animar-me comendo, bebendo um copo, fumando ou outra coisa do género				
29	Confiar na minha própria experiência e na competência que tenho adquirido				
30	Experimentar várias soluções até encontrar uma que resulte				
31	Estabelecer uma ordem de prioridades e concentrar-me nas coisas mais importantes				
32	Procurar ver o que há de positivo em cada situação				
33	Ser firme com a pessoa de quem cuido e fazer-lhe ver o que espero dela				
34	Pensar que ninguém tem culpa da situação				
35	Descarregar o excesso de energia e sentimentos, andando, nadando ou fazendo outro exercício físico				
36	Reunir regularmente com um grupo de pessoas com problemas semelhantes				
37	Usar técnicas de relaxamento, meditação ou outras				
38	Dedicar-me a coisas que me interessam, para além de cuidar da pessoa				

Annex – VII

Attribution Questionnaire 27

Questionário N.º	4
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Data:			
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Código do Participante	
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AVALIAÇÃO DE ESTIGMA QUESTIONÁRIO DE ATRIBUIÇÃO 27

Por favor leia a seguinte informação sobre José

José é um homem com 30 anos de idade, solteiro e com esquizofrenia/depressão/doença de Crohn. Apesar de as vezes o José ficar perturbado, nunca foi violento. Como a maior parte de pessoas com esquizofrenia, o José não é mais perigoso do que outra pessoa qualquer. Ele vive num apartamento e trabalha como estafeta num escritório de advogados. Os seus sintomas são habitualmente controlados com a medicação apropriada.

Agora responde a cada uma das questões que se seguem sobre o José. Marque com uma cruz o número que melhor corresponde à sua resposta,

1. Eu iria sentir-me incomodado pelo José.

1	2	3	4	5	6	7	8	9
Nada								Muito

2. Eu iria sentir-me inseguro perto do José

1	2	3	4	5	6	7	8	9
Não, Nada								Muito

3. O José iria assustar-me

1	2	3	4	5	6	7	8	9
Nada								Muito

4. Até que ponto ficaria zangado com o José

1	2	3	4	5	6	7	8	9
Nada								Muito

5. Se eu fosse responsável pelo tratamento do José, pediria para ele tomar a medicação

1	2	3	4	5	6	7	8	9
Nada								Muito

6. Penso que José coloca a sua vizinhança em risco se não for internado.

1	2	3	4	5	6	7	8	9
Nada								Muito

7. Se eu fosse um empregador, entrevistaria o José para um emprego.

1	2	3	4	5	6	7	8	9
Nada								Muito

Questionário N.º	4
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Data:			
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Código do Participante	
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8. Eu estaria disposto a conversar com o José sobre os seus problemas.

1	2	3	4	5	6	7	8	9
Nada								Muito

9. Eu iria sentir piedade pelo José.

1	2	3	4	5	6	7	8	9
Nada								Muito

10. Eu iria pensar que o José é culpado da sua situação actual.

1	2	3	4	5	6	7	8	9
Nada								Muito

11. Até que ponto acha que é contralável a causa da situação actual do José.

1	2	3	4	5	6	7	8	9
Nada								Muito

12. Até que ponto se sentiria irritado com o José?

1	2	3	4	5	6	7	8	9
Nada								Muito

13. Até que ponto sentiria que o José é perigoso?

1	2	3	4	5	6	7	8	9
Nada								Muito

14. Até que ponto concorda que José deveria ser forçado a tratar-se com o seu médico mesmo que ele não quisesse?

1	2	3	4	5	6	7	8	9
Nada								Muito

15. Eu penso que seria melhor para a comunidade onde o José está inserido se ele fosse colocado num hospital psiquiátrico.

1	2	3	4	5	6	7	8	9
Nada								Muito

16. Eu partilharia uma boleia de carro com o José, todos os dias.

1	2	3	4	5	6	7	8	9
Nada								Muito

17. Até que ponto acha que um asilo, onde o José pudesse estar afastado da sua vizinhança, seria o melhor local para ele?

1	2	3	4	5	6	7	8	9
Nada								Muito

Questionário N.º	4
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Data:			
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Código do Participante	
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18. Eu iria sentir-me ameaçado pelo José

1	2	3	4	5	6	7	8	9
Nada								Muito

19. Até que ponto sentiria medo do José?

1	2	3	4	5	6	7	8	9
Nada								Muito

20. Até que ponto estaria disposto a ajudar o José?

1	2	3	4	5	6	7	8	9
Nada								Muito

21. Até que ponto tem a certa de que iria ajudar o José?

1	2	3	4	5	6	7	8	9
Nada								Muito

22. Até que ponto sentiria pena do José?

1	2	3	4	5	6	7	8	9
Nada								Muito

23. Até que ponto acha que o José é responsável pela sua situação atual?

1	2	3	4	5	6	7	8	9
Nada								Muito

24. Até que ponto se iria sentir assustado pelo José?

1	2	3	4	5	6	7	8	9
Nada								Muito

25. Se eu fosse responsável pelo tratamento do José, iria forçá-lo a viver numa residência comunitária.

1	2	3	4	5	6	7	8	9
Nada								Muito

26. Se eu fosse senhorio, provavelmente alugaria um apartamento ao José.

1	2	3	4	5	6	7	8	9
Nada								Muito

27. Até que ponto se iria preocupar com o José?

1	2	3	4	5	6	7	8	9
Nada								Muito

Annex – VIII

Perceived Stress Scale

Questionário N.º	5
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Data:			
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Código do Participante	
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ESCALA DE PERCEÇÃO DE STRESS (Tradução de J.L. Pais Ribeiro & T. Marques [2009])

Nesta escala fazemos perguntas acerca dos seus sentimentos e pensamentos que ocorreram **no último mês**. Em cada uma pedimos para indicar com que frequência se sentiu ou pensou de determinada maneira. Embora algumas das questões sejam parecidas, há diferenças entre elas e deverá responder a cada uma como uma questão diferente. A melhor maneira de o fazer é responder a cada questão rapidamente. Ou seja, não se preocupe em lembrar do número de vezes que se sentiu de determinada maneira. Em vez disso assinala a alternativa que lhe pareça uma estimativa razoável. As alternativas que pode escolher são: “Nunca”; “Quase Nunca”, “Algumas vezes”; “Com muita frequência”; e “Muitas Vezes”.

	Nunca	Quase Nunca	Algumas vezes	Com muita frequência	Muitas vezes
1. No último mês com que frequência se sentiu aborrecido com algo que ocorreu inesperadamente? *					
2. No último mês com que frequência sentiu que era incapaz de controlar as coisas que são importantes na sua vida? *, **					
3. No último mês com que frequência se sentiu nervoso ou “stressado”? *					
4. No último mês com que frequência enfrentou com sucesso coisas aborrecidas e chatas? (1)					
5. No último mês com que frequência sentiu que estava a enfrentar com eficiência mudanças importantes que estavam a ocorrer na sua vida? (1)					
6. No último mês com que frequência se sentiu confiante na sua capacidade para lidar com os seus problemas pessoais? *, **, (1)					
7. No último mês com que frequência sentiu que as coisas estavam a correr como queria? *, **, (1)					
8. No último mês com que frequência reparou que não conseguia fazer todas as coisas que tinha que fazer? *					
9. No último mês com que frequência se sentiu capaz de controlar as suas irritações? *, (1)					

Questionário N.º	8
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Data:			
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Código do Participante	
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	Nunca	Quase Nunca	Algumas vezes	Com muita frequência	Muitas vezes
10. No último mês com que frequência sentiu que as coisas lhe estavam a correr pelo melhor? *, (1)					
11. No último mês com que frequência se sentiu irritado com coisas que aconteceram e que estavam fora do seu controlo? *					
12. No último mês com que frequência foi capaz de controlar o seu tempo?					
13. No último mês com que frequência sentiu que as dificuldades se acumulavam ao ponto de não ser capaz de as ultrapassar? *, **					
Totais:					

*- Itens da versão de 10 itens; **- itens da versão de quatro itens; (1)-Itens invertidos

Obrigado pela sua participação.

Para o avaliador:

Instruções para cotação:

1- A pontuação é dada de 0 a 4 valores e os itens assinalados com (1) devem ser invertidos

2- A pontuação total é o somatório de todos os itens.

Pontuações mais altas indicam mais stress percebido.

Annex – IX

Authorization request for data collection at Casa de Saúde do Bom Jesus

Rogério João Mulumba
Rua Nova Santa Cruz, 609 5º
C 4710-409 Braga

**Exma. Srª Directora da
Casa de Saúde do Bom Jesus**

Assunto: Pedido de autorização para pesquisa.

Rogério João Mulumba, a frequentar o curso de Mestrado em Ciências de Saúde na Escola de Ciências de Saúde da Universidade do Minho, vem por este meio solicitar a Vossa Excelência, que seja concedida autorização para que possa aplicar os questionários aos cuidadores informais (familiares) dos pacientes desta Unidade Sanitária e a consulta dos processos para extrair a informação sobre o diagnóstico e o número de internamentos dos pacientes.

Este pedido surge no contexto da investigação sobre Burnout e sobrecarga dos cuidadores informais de pacientes com doença psiquiátrica e não psiquiátrica, cujo título é “Characterization of Burnout in Caregivers of Patients with Psychiatric Disorder” (Caracterização do Burnout dos cuidadores de pacientes com doença psiquiátrica), tem como orientadora a Dra Nadine Santos e coorientador o Prof. Dr. Pedro Morgado.

Este estudo tem como objetivo:

- Avaliar o nível de sobrecarga e o Burnout dos cuidadores informais de pacientes com transtorno psiquiátrico, utilizando como controle cuidadores informais de pacientes com doença crónica não-psiquiátrica.
- Quantificar a correlação entre o Burnout e os seguintes fatores em cuidadores informais: estresse, grau de estigma, estratégias de coping e doença psiquiátrica no cuidador.

Gostaria que este contacto com os cuidadores informais e os processos dos pacientes decorresse entre os meses de Novembro 2016 a Maio de 2017.

Comprometo-me ao sigilo de dados e a enviar os resultados da pesquisa, se assim o entenderem.

Agradeço antecipadamente a atenção dispensada e fico ao dispor.

Braga, 16 de Setembro de 2016


Rogério João Mulumba

Rogério João Mulumba
Rua Nova Santa Cruz, 609 5º
C 4710-409 Braga

Exmo. Senhor

Presidente da Comissão de Ética para saúde da Casa de Saúde do Bom Jesus

Assunto: Pedido de autorização para pesquisa.

Rogério João Mulumba, na qualidade de Investigador Principal, vem por este meio, solicitar a V.Ex.^a autorização para realizar na Casa de Saúde do Bom Jesus o Estudo de Investigação cujo título é “Characterization of Burnout in Caregivers of Patients with Psychiatric Disorder” (Caracterização do Burnout dos cuidadores de pacientes com doença psiquiátrica), de acordo com o programa de trabalhos e os meios apresentados no projeto em anexo.

Comprometo-me ao sigilo de dados e a enviar os resultados da pesquisa, se assim o entenderem.

Agradeço antecipadamente a atenção dispensada e fico ao dispor.

Braga, 16 de Setembro de 2016



Rogério João Mulumba

Annex – X

Authorization request for data collection at Hospital de Braga

Exmo. Sr Presidente da Comissão Executiva do Hospital de Braga

Braga

Rogério João Mulumba, médico a frequentar o curso de Mestrado em Ciências de Saúde na Escola de Ciências de Saúde da Universidade do Minho, vem por este meio solicitar a Vossa Excelência, que seja concedida autorização para que possa aplicar os questionários aos cuidadores informais (familiares) dos pacientes dos serviços de psiquiatria e de medicina interna, e a consulta dos processos para extrair a informação sobre o diagnóstico e o número de internamentos dos respetivos pacientes.

Este pedido surge no contexto da investigação sobre Burnout e sobrecarga dos cuidadores informais de pacientes com doença psiquiátrica e não psiquiátrica, cujo título é “Characterization of Burnout in Caregivers of Patients with Psychiatric Disorder” (Caracterização do Burnout dos cuidadores de pacientes com doença psiquiátrica), tem como orientadora a Dra Nadine Santos e coorientador o Prof. Dr. Pedro Morgado.

Este estudo tem como objetivo:

- Avaliar o nível de sobrecarga e o Burnout dos cuidadores informais de pacientes com transtorno psiquiátrico, utilizando como controle cuidadores informais de pacientes com doença crónica não-psiquiátrica.
- Quantificar a correlação entre o Burnout e os seguintes fatores em cuidadores informais: estresse, estigma, estratégias de coping e doença psiquiátrica no cuidador.

Gostaria que este contacto com os cuidadores informais e os processos dos pacientes decorresse entre os meses de Novembro de 2016 a Maio de 2017.

Comprometo-me ao sigilo de dados e a enviar os resultados da pesquisa, se assim o entenderem.

Agradeço antecipadamente a atenção dispensada e fico ao dispor. Pelo que pede deferimento

Braga, 17 de Novembro de 2016



Rogério João Mulumba



Rogério João Mulumba
Rua Nova Santa Cruz, 609 5º
C 4710-409 Braga

**Exma. Sr Director do
Serviço de Psiquiatria do Hospital de Braga**

Assunto: Pedido de autorização para pesquisa.

Rogério João Mulumba, a frequentar o curso de Mestrado em Ciências de Saúde na Escola de Ciências de Saúde da Universidade do Minho, vem por este meio solicitar a Vossa Excelência, que seja concedida autorização para que possa aplicar os questionários aos cuidadores informais (familiares) dos pacientes deste serviço de psiquiatria e a consulta dos processos para extrair a informação sobre o diagnóstico e o número de internamentos dos respetivos pacientes.

Este pedido surge no contexto da investigação sobre Burnout e sobrecarga dos cuidadores informais de pacientes com doença psiquiátrica e não psiquiátrica, cujo título é "Characterization of Burnout in Caregivers of Patients with Psychiatric Disorder" (Caracterização do Burnout dos cuidadores de pacientes com doença psiquiátrica), tem como orientadora a Dra Nadine Santos e coorientador o Prof. Dr. Pedro Morgado.

Este estudo tem como objetivo:

- Avaliar o nível de sobrecarga e o Burnout dos cuidadores informais de pacientes com transtorno psiquiátrico, utilizando como controle cuidadores informais de pacientes com doença crónica não-psiquiátrica.
- Quantificar a correlação entre o Burnout e os seguintes fatores em cuidadores informais: estresse, estigma, estratégias de coping e doença psiquiátrica no cuidador.

Gostaria que este contacto com os cuidadores informais e os processos dos pacientes decorresse entre os meses de Novembro de 2016 a Maio de 2017.

Comprometo-me ao sigilo de dados e a enviar os resultados da pesquisa, se assim o entenderem.

Agradeço antecipadamente a atenção dispensada e fico ao dispor.

Braga, 17 de Novembro de 2016



Rogério João Mulumba

Rogério João Mulumba
Rua Nova Santa Cruz, 609 5º
C 4710-409 Braga

**Exma. Sr Director do
Serviço de Medicina Interna do Hospital de Braga**

Assunto: Pedido de autorização para pesquisa.

Rogério João Mulumba, a frequentar o curso de Mestrado em Ciências de Saúde na Escola de Ciências de Saúde da Universidade do Minho, vem por este meio solicitar a Vossa Excelência, que seja concedida autorização para que possa aplicar os questionários aos cuidadores informais (familiares) dos pacientes deste serviço de medicina interna e a consulta dos processos para extrair a informação sobre o diagnóstico e o número de internamentos dos respetivos pacientes.

Este pedido surge no contexto da investigação sobre Burnout e sobrecarga dos cuidadores informais de pacientes com doença psiquiátrica e não psiquiátrica, cujo título é "Characterization of Burnout in Caregivers of Patients with Psychiatric Disorder" (Caracterização do Burnout dos cuidadores de pacientes com doença psiquiátrica), tem como orientadora a Dra Nadine Santos e coorientador o Prof. Dr. Pedro Morgado.

Este estudo tem como objetivo:

- Avaliar o nível de sobrecarga e o Burnout dos cuidadores informais de pacientes com transtorno psiquiátrico, utilizando como controle cuidadores informais de pacientes com doença crónica não-psiquiátrica.
- Quantificar a correlação entre o Burnout e os seguintes fatores em cuidadores informais: estresse, estigma, estratégias de coping e doença psiquiátrica no cuidador.

Gostaria que este contacto com os cuidadores informais e os processos dos pacientes decorresse entre os meses de Novembro de 2016 a Maio de 2017.

Comprometo-me ao sigilo de dados e a enviar os resultados da pesquisa, se assim o entenderem.

Agradeço antecipadamente a atenção dispensada e fico ao dispor.

Braga, 17 de Novembro de 2016



Rogério João Mulumba

Annex – XI

Authorization for data collection at Hospital de Braga



Comissão de Ética para a Saúde

N/Ref^o: CESHB-157/2016

Relator: Juan R Garcia

Parecer emitido em reunião de 06 de dezembro 2016

Nos termos dos Nº 1 e 6 do Artigo 16º da Lei Nº 21/2014, de 16 de Abril, a Comissão de Ética para a Saúde do Hospital de Braga (CESHB), emite o seguinte parecer relativo ao estudo "*Caracterização do Burnout em cuidadores de doentes com doença psiquiátrica*", de que é investigador principal o Dr. Rogério João Mulumba, aluno do Mestrado Integrado da ECS-UM, e orientadora a Dra. Nadine Santos, e coorientador o Prof. Dr. Pedro Morgado, e que decorrerá no Serviço de Psiquiatria da instituição.

Não existem estudos de Burnout nos cuidadores informais de pacientes em geral e psiquiatria em particular. Pretende-se avaliar o nível de Burnout de cuidadores informais (familiares, irmãos, tios, avós, a pessoa que cuida do paciente quando tem alta) de pacientes com transtornos psiquiátricos, usando como controle cuidadores informais de pacientes com doença crónica não psiquiátrica.

O estudo pretende fornecer mais informações sobre a saúde psicológica dos cuidadores informais, de modo a promover uma discussão sobre as estratégias ideais a seguir para a manutenção do bem-estar do doente após a alta e prevenção das readmissões, bem como a saúde mental do cuidador.

Estratégias ideais a seguir para a manutenção do bem-estar do doente após a alta e prevenção das readmissões, sem deixar de lado a saúde mental do seu cuidador.

São os objetivos: avaliar o nível de sobrecarga e o Burnout dos cuidadores informais de pacientes com transtorno psiquiátrico; e quantificar a correlação entre o Burnout e

os fatores seguintes: stress, estigma, estratégias de coping e doença psiquiátrica no cuidador.

A população a estudar é constituída por Cuidadores de pacientes seguidos na consulta e internamento de Psiquiatria do Hospital com o diagnóstico de Esquizofrenia ou de Depressão; e Cuidadores de pacientes em seguimento na consulta e internamento de Medicina do Hospital de Braga com o diagnóstico de Doença de Crohn.

Serão incluídos todos Cuidadores que prestem o seu consentimento e preencham todas as condições seguintes (critérios de inclusão) e nenhum dos critérios de exclusão: serem maiores de 18 anos; o cuidador por mais de um ano, sem pagamento; o cuidador que passa mais tempo com o paciente em casa; o cuidador que geralmente visita o paciente durante o internamento; o paciente deve ter um dos diagnósticos alvos por mais de um ano; deve ter mais de uma hospitalização.

A amostra será composta por 180 cuidadores informais divididos em 3 grupos: um de 60 cuidadores informais de pacientes com esquizofrenia, outro segundo de 60 cuidadores informais de pacientes com depressão e outro de 60 cuidadores informais de pacientes com doença de Crohn.

Os dados sociodemográficos e história médica dos pacientes incluindo o número de readmissões, será extralido a partir dos registos do hospital após a respetiva autorização.

Após marcação telefónica e no período em que os cuidadores visitam seus pacientes, os questionários a solicitar serão: demográfico (Questionário 1), o Inventário de Burnout de Maslach (Questionário 2), o Inventário de Estratégias de Coping (Questionário 3), o Questionário de Atribuição-27 (Questionário 4) e a Escala de Estresse Percebido (Questionário 5).

Os inquéritos serão todos anónimos, atribuindo-se a cada sujeito, no momento da inclusão no estudo, um código de identificação único, e que apenas o investigador principal terá acesso à correspondência entre o nome do paciente e o código de identificação do cuidador.

O projeto não tem nenhum financiamento nem implica custos para o Hospital de Braga.

A cronologia prevista vai de Novembro de 2016 a Maio de 2017.

O pedido consta dos seguintes documentos anexados:

Formulário CESHB

Protocolo do estudo

Questionários 1 a 5, como acima referido

CV do investigador

Pedido de autorização dos Diretores Serviços de Medicina e Psiquiatria,

Modelo de Consentimento Informado

O estudo foi avaliado em reunião ordinária da Comissão de Ética, tendo sido aprovado por nada haver.

Braga, 12 de Dezembro de 2016

O Presidente da Comissão de Ética



(Juan R. Garcia)

Annex – XII

Authorization for data collection at Casa de Saúde do Bom JESUS

PARECER DA COMISSÃO DE ÉTICA

A Comissão de Ética da Casa de Saúde do Bom Jesus, após analisar o pedido de autorização para aplicar os questionários aos cuidadores informais (familiares), dos doentes desta Unidade de Saúde e a consulta dos processos para obter informação sobre o diagnóstico e o número de internamentos, de **Rogério João Mulumba**, Mestrando da Escola de Ciências da Saúde da Universidade do Minho, deu parecer positivo.

O estudo deverá salvaguardar a total confidencialidade dos dados obtidos.

Braga, 19 de setembro de 2016

O Presidente



Dr. António Guimarães