JOANA FILIPA DOS SANTOS

CAREGIVERS' AND HEALTHCARE PROFESSIONALS' PERSPECTIVES ON CAREGIVER'S BURDEN ON NEURODEGENERATIVE DISEASES

Dissertação de Mestrado de Prática Avançada de Fisioterapia em Neurologia

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Fevereiro 2023

Relatório de Investigação apresentado para cumprimento dos requisitos necessários à obtenção do grau de Mestre em Fisioterapia em Neurologia, realizado sob a orientação científica de Professora Doutora Raquel Bouça-Machado.

DECLARAÇÕES

Declaro que este Relatório de Projeto de Investigação é o resultado da minha investigação pessoal e independente. O seu conteúdo é original e todas as fontes consultadas estão devidamente mencionadas no texto, nas notas e na bibliografia.

Lisboa, 24 de fevereiro de 2023

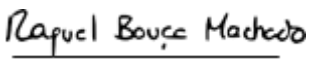
A candidata,

Joana Santos

Declaro que este Relatório de Projeto de Investigação se encontra em condições de ser apresentado a provas públicas.

Torres Vedras, 24 de fevereiro de 2023

A orientadora,



Raquel Bouça-Machado

DEDICATÓRIA

Ao Gustavo.

Que nasças num mundo onde é possível cresceres
e seres tudo aquilo que sonhares.

AGRADECIMENTOS

Neste processo de crescimento, não só académico como pessoal, seria impensável não reconhecer o mérito de todos os que para ele contribuíram.

Em primeiro lugar, à Prof. Dr.ª Raquel, por todo o empenho, exigência e paciência que sempre me mostrou e que fez com que este projeto chegasse a bom porto.

À Prof. Dr.ª Leonor Correia Guedes, que me acolheu e tanto me ensinou.

Ao serviço de Neurologia do Hospital de Santa Maria, à Inês, à Vanessa, pela ajuda e disponibilidade que sempre me mostraram.

À Sara, pela disponibilidade, leveza e empatia com que sempre me ouviu.

Àqueles que, sem poder contribuir diretamente para este projeto, mantiveram o mundo a girar quando eu precisei que o tempo abrandasse:

os meus pais, por todo esforço e trabalho árduo, que jamais serei capaz de retribuir, sempre garantiram que me fosse atingível o que nunca lhes foi possível ter;

a minha irmã, por ser exatamente o que uma família deve ser;

o meu marido, por me mostrar que podemos sempre ser do tamanho dos nossos sonhos.

RESUMO

PERSPETIVAS DE CUIDADORES E PROFISSIONAIS DE SAÚDE SOBRE O DESGASTE DO CUIDADOR NAS DOENÇAS NEURODEGENERATIVAS

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INTRODUÇÃO: As doenças neurodegenerativas (NDD) são doenças progressivas e debilitantes, que condicionam a dependência do doente e, consequentemente, a necessidade de cuidados. Relata-se que cerca de 33,3% dos cuidadores de doentes com NDD sofrem de desgaste do cuidador moderado a grave. O desgaste do cuidador está associado a um risco acrescido de problemas de saúde, física e mental, assim como à institucionalização precoce dos doentes. O principal fator contribuinte e as estratégias de minimização de risco para este problema ainda não são conhecidos. O objetivo deste estudo é explorar as perspetivas dos cuidadores informais e profissionais de saúde sobre estes dois aspetos cruciais do desgaste do cuidador associado às NDD.

MÉTODOS: Foi elaborado e disseminado um questionário, em formato on-line e em papel, através de redes sociais, instituições de saúde e associações nacionais de doentes. Os profissionais de saúde e os cuidadores de doentes com NDD foram convidados a participar.

RESULTADOS: Uma amostra total de 172 participantes respondeu ao questionário (100 cuidadores e 72 profissionais de saúde). Os fatores contribuintes mais reportados foram a dependência do doente (n=46, 9%), falta de tempo livre do cuidador (n=33, 6%) e desinformação (n=29, 6%). As alterações comportamentais dos doentes (4,5 ± 0,9) e a dependência nas atividades da vida diária (4,5 ± 1,0) foram classificadas como tendo um impacto significativo no bem-estar dos cuidadores. As estratégias de minimização de risco mais

reportadas incluíram apoio socioeconómico (n=122, 24%), maior consciencialização sobre a doença (n=52, 10%) e acesso facilitado a cuidados especializados para o doente (n=50, 10%).

CONCLUSÕES: Na opinião dos cuidadores e profissionais de saúde, a dependência do doente, a falta de tempo livre do cuidador e a desinformação são os principais fatores de desgaste do cuidador. De acordo com os resultados deste estudo, a melhor estratégia de prevenção de desgaste do cuidador é uma intervenção precoce que inclui ambas estratégias diretas e indiretas (ex.: através do doente) ao cuidador.

PALAVRAS-CHAVE: doenças neurodegenerativas; desgaste do cuidador; sobrecarga do cuidador; doença de Alzheimer, doença de Parkinson, doença de Huntington, ataxia espinocerebelosa.

ABSTRACT

CAREGIVERS' AND HEALTHCARE PROFESSIONALS' PERSPECTIVES ON CAREGIVERS' BURDEN ON NEURODEGENERATIVE DISEASES

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INTRODUCTION: Neurodegenerative diseases (NDD) are progressive and debilitating conditions that lead to dependence and need of care. Evidence shows 33,3% of caregivers of NDD patients suffer from moderate to severe burden. An increased risk of mental and physical health problems as well as patients' early admission into nursing homes are both associated with the burden of caregiving. Currently, the main contributing factor and risk minimization strategies are not yet established. This study aims to explore the perspectives of caregivers and healthcare professionals on these two crucial aspects of caregivers' burden associated with NDD.

METHODS: An online and paper-based survey was disseminated through social network, healthcare institutions outpatient clinic and national patient associations. Healthcare professionals and caregivers of patients with NDD were invited to participate.

RESULTS: A total sample of 172 participants answered the survey (100 caregivers and 72 health professionals). The most reported contributing factors were the patient's dependency (n=46, 9%), caregiver's lack of free time (n=33, 6%), and misinformation (n=29, 6%). Patients' behavioral changes (4,5 ± 0,9) and dependence on daily activities (4,5 ± 1,0) were rated as having a significant impact on caregivers' wellbeing. The most reported risk minimization strategies included socioeconomic support (n=122, 24%), greater awareness of diseases (n=52, 10%), and easier access to specialized care (n=50, 10%).

CONCLUSIONS: Patient's dependency, caregivers lack of free time and misinformation are, in caregivers and healthcare professionals' opinion, the main factors for caregivers' burden. According to study results, the best way to avoid caregiver burden situations is an early intervention that includes both direct and indirect (i.e., through the patient) interventions on the caregiver.

KEY-WORDS: neurodegenerative diseases; caregiver's burden; Alzheimer's disease, Parkinson's disease, Huntington's disease, spinocerebellar ataxia.

LISTA DE ABREVIATURAS

AD – Alzheimer's disease

BI – Barthel Index

CAML – Centro Académico de Medicina de Lisboa

CG – Caregiver

CHULN – Centro Hospitalar Universitário Lisboa Norte

CNS – CNS | Campus Neurológico

HCP – Healthcare professionals

NDD – Neurodegenerative diseases

PD – Parkinson's disease

ZBI – Zarit Burden Interview

ÍNDICE

INTRODUCTION

Neurodegenerative diseases (NDD) is an umbrella term for a set of incurable, progressive and debilitating conditions caused by nerve cells degeneration (Dugger & Dickson, 2017; Erkkinen et al., 2018). Alzheimer's disease (AD) and Parkinson's disease (PD) are the two most prevalent (Erkkinen et al., 2018; Reith, 2018). NDD are viewed as an age-related disease. In the coming decades, it is anticipated that the prevalence of NDD will rise as people live longer (Erkkinen et al., 2018; Reith, 2018). Given the progressive and fluctuating character of these diseases, the presence of a diverse spectrum of motor and non-motor symptoms and variable response to therapeutic interventions, patients with NDD experience a slow and progressive loss of function and autonomy, resulting in an increasing dependence on others (Erkkinen et al., 2018; Qutub et al., 2014).

Caregivers (CG), often close family members who share household with the patient, have a crucial role in patients' lives. In addition to providing the majority of care, they also assist them with daily activities and offer them emotional, physical, and occasionally, financial support (Liu et al., 2020; Qutub et al., 2014). The care of a family member (or another person) typically occurs for long periods of time and overlaps with other caregivers' personal and/or familiar responsibilities, which frequently leads to a marked increase in daily stress (Liu et al., 2020). Caregiver's burden is the self-perceived and multifaceted strain endured by someone caring for an ill or disabled person over time (Liu et al., 2020; Tramonti et al., 2019). High levels of burden have adverse outcomes including decreased quality of life, physical and psychological health problems such as increased cardiovascular risk, sleep disturbances, anxiety and/or depression, and reduced ability to provide high-quality care to the patient (Liu et al., 2020). According to the published evidence, caregiver's burden depends on both CG's and patient's characteristics (Lloyd et al., 2019). Factors such as insufficient financial resources, conflict of multiple responsibilities, lack of leisure time and long-term care, seem to contribute to higher rates of burden (Liu et al., 2020).

Due to the complexity and increasing reliance on third parties, NDD is associated with high levels of caregiver burden (Krutter et al., 2020; Liu et al., 2020b; Roland & Chappell, 2019; Tramonti et al., 2019). According to the published evidence, 33,3% of caregivers of NDD patients seem to suffer from moderate to severe burden (Lithin et al., 2020). Disease severity, patient's functional impairment and presence of non-motor symptoms seem to be important contributes to the presence of caregiver's burden (Chiao et al., 2015; Dauphinot et al., 2015;

Kim et al., 2012; Kudlicka et al., 2014; Macchi et al., 2020; Nene & Yadav, 2020; Seidel & Thyrian, 2019). This frequently leads to the premature institutionalization of patients, which has a detrimental effect on their physical and mental health and raises expenses for the family and society (Krutter et al., 2020; Nene & Yadav, 2020; Ransmayr, 2021).

Currently, the main contributing factors and risk minimization strategies of burden have not yet been defined in the field of NDD. Due to the crucial role CGs and multidisciplinary teams play in managing these complex diseases, a survey exploring their viewpoint on the main contributing factors and risk minimization strategies of caregiver's burden on NDD patients was conducted. Based on the results, recommendations are made.

METHODS

Study design

An online and paper-based survey was conducted between June 2022 and January 2023.

The study protocol was approved by the ethics committees of CNS | Campus Neurológico (Ref. nº5-2022) and Centro Académico de Medicina de Lisboa (CAML) (Ref. nº204/22).

Participants

CGs were eligible for the study if they had 18 years old or more and cared for a person diagnosed with a neurodegenerative disease (Parkinson's disease or a parkinsonian syndrome, Alzheimer's disease or other type of dementia, Amyotrophic lateral sclerosis, Friedreich ataxia or other type of spinocerebellar ataxia, hereditary spastic paraplegia, Huntington's disease). Healthcare professionals (HCP) were included if qualified and working with neurodegenerative disease patients. All participants were also required to be able and willing to provide informed consent to participate in the study.

Study procedures

A survey with two versions, one intended for CGs and the other for HCPs, was created specifically for this study (Appendix I and II). Both versions were anonymous and consisted of four main sections: sample's characterization; the concept of burden; contributing factors; and possible risk minimization strategies.

Sample characterization

Sample characterization included questions on demographic data (age, gender, education level, occupational and financial status) and patients clinical characteristics (age, diagnosis, time since diagnosis and functional independence).

Care-related aspects for CGs included number of care-receivers, relationship to patient, years caring, time spent per day caring and level of burden. For HCPs was asked the type of health institution and years of experience treating people with NDD.

Patients' functional independence was assessed through the Portuguese version of the Barthel Index for Activities of daily living (BI), a self-report measurement of patients' performance during activities of daily living (Araújo et al., 2007).

Level of burden was assessed using Zarit Burden Interview (ZBI), a self-report measurement of caregiver's burden, consisting of a 22-item scale with a 5-point Likert scale, validated and translated to Portuguese in 2010 (Ferreira et al., 2010).

The concept of burden

It is necessary to acknowledge and comprehend the concept to address caregiver's burden. We therefore examined the perspectives of CGs and HCPs on this notion as a secondary goal of this study. Before receiving a formal definition of a caregiver's burden, participants were asked to list three words that, in their opinion, best characterized this concept.

Risk Factors

This section was divided into two steps. In the first, participants were asked to spontaneously mention three risk factors for caregivers' burden.

In the second section, participants rated a given list of potential risk factors based on their perception of how they might influence caregiver burden. A Likert scale was used for this purpose, with 1 denoting "no influence" and 5 denoting "high influence."

Minimization strategies

Participants were asked to spontaneously list three possible risk-minimization strategies that they thought might be helpful.

Additionally, a list of the top three recommendations used by HCPs in clinical practice was requested.

Survey pretest

Before the survey was made widely available, a feasibility pretest with five CG and five HCP was carried out to reduce comprehension and usability errors. Both paper and online versions of the survey were completed by participants. Based on the comments and suggestions given, the survey was improved.

Survey dissemination

The survey was distributed through the channels of communication (social networks and email) of the national patient associations and of private health institutions.

Since not all CGs have the same ease of access or familiarity with technological tools, in addition to the online version, a paper version of the survey was also used. This was mainly

distributed in the outpatient clinic of a tertiary university hospital (Hospital Santa Maria, Lisbon, Portugal).

Before having access to the survey itself, all participants were informed about objectives, duration, procedures and voluntariness of the study and gave their informed consent (appendix III).

Both versions made it explicit that participants could leave the survey at any time without it having any negative repercussions on them.

Data analysis

Descriptive statistics were used to analyze the results of the survey. Mean, standard deviation, median and range of values were calculated for all continuous variables while absolute and relative frequencies were used for the categorical data.

The primary outcome was a composite of the main contributing factors and risk minimizations strategies to prevent caregivers burden mentioned by CGs and HCPs, when questioned about the topic. The terms most frequently associated with the concept of caregiver's burden, by CGs and HCPs, were analyzed as a secondary outcome.

Due to the lack of published evidence on the topic, it was not possible to conduct a formal sample size calculation. A convenience sample of 150 participants (100 CGs and 50 HCPs) was determined to be needed to respond to the primary outcome.

Based on previous published evidence, categories were created to group and quantitatively analyze the answers regarding the concept of burden, risk factors and minimization strategies. Due to the presence of a high heterogeneity in the answers, only those mentioned at least five times, were considered for analysis. All others were classified as "others".

Statistical analysis was performed using Microsoft Excel (Microsoft, Seattle, WC, USA) and SPSS® version 21.0 (SPSS Inc. Chicago, IL.USA).

RESULTS

Ten participants (5 CGs, 5 HCPs) performed the survey feasibility pretest in both online and paper-version. Based on the results, the section 'concept of caregiver's burden' in HCPs questionnaire was improved.

A sample of 172 participants was recruited, 100 CGs (78% female, mean age of 52,32±12,54 years and mean years caring of 7,99±6,88) and 72 HCPs (59% female, mean age of 34,80±9,92 years, mean years of experience working with NDD patients of 9,96±8,89 years). Table 1 summarizes participants characteristics.

Table 1 – Demographical and clinical characteristics of the sample. Higher ZBI scores reveal higher caregiver's burden. Higher BI scores indicate higher patient's functional dependency.

Caregivers' characteristics (n=100)		
Age (Mean, SD)		52,32 ± 12,54
Female sex (n (%))		78 (78%)
Education Level (n (%))	Primary education	18 (18%)
	Secondary education	28 (28%)
	Tertiary education	54 (54%)
Financial status (n (%))	With difficulty covering usual expenses	21 (21%)
	Without difficulty in covering usual expenses, unable to cover extra expenses	33 (33%)
	Without difficulty in covering usual expenses and extra expenses	42 (42%)
Occupational status (n (%))	Unemployed	10 (10%)
	Full-time employed (on-site)	2 (2%)
	Full-time employed (remote)	52 (52%)
	Part-time employed	7 (7%)
	Retired	26 (26%)

	Unpaid leave	3 (3%)
Years of caring (Mean, SD)		7,99 ± 6,88
Daily hours of caring (Mean, SD)		10,04 ± 9,54
ZBI (Mean, SD)		36,79 ± 18,30
Number of care-recipients (Mean, SD)		1,82 ± 0,38
Caring for >1 person (n (%))		17 (17%)
Relationship to care-recipient (n (%))	Daughter/Son	44 (44%)
	Spouse	38 (38%)
	Parent	12 (12%)
	Other relative	6 (6%)
Living with the care-recipient (n (%))		72 (72%)
Patients' characteristics (n=100)		
Age (Mean, SD)		66,43 ± 16,69
Diagnosis (n (%))	Parkinson's disease or another parkinsonian syndrome	39 (39%)
	Alzheimer's disease or other type of dementia	22 (22%)
	Huntington's disease	22 (22%)
	Spinocerebellar ataxia	11 (11%)
	Others	6 (6%)
Years of disease (Mean, SD)		11,2 ± 7,44
BI (Mean, SD)		56,53 ± 30,94
Healthcare professionals' characteristics (n=72)		
Age (Mean, SD)		34,80 ± 9,92
Female sex (n (%))		59 (82%)

Profession (n (%))	Medical doctor	27 (38%)
	Physiotherapist	25 (35%)
	Nurse	11 (15%)
	Psychologist	3 (4%)
	Others	6 (8%)
Experience with NDD (Mean, SD)		9,96 ± 8,89
Work environment (n (%))	Hospital	46 (37%)
	Private practice	35 (28%)
	Home service	21 (17%)
	Continuous care facilities	18 (15%)
	Others	2 (2%)
	61% of healthcare professionals work simultaneously in more than 1 location	

All HCP and 90% (n=90%) of CG believe that exists an association between NDD and caregiver's burden.

Risk factors for caregiver's burden

Globally, the most frequently mentioned main risk factors to caregivers' burden (Fig.1) were patient's dependency (n=46, 9%), lack of time for themselves (n=33, 6%) and misinformation (n=29, 6%).

CGs' answers analysis showed patient's dependency (n=30, 10%), lack of time for themselves (n=21, 7%) and fatigue (n=19, 6%) were the factors most frequently reported. Half of the CGs (n=50 50%) said that all the cited factors applied to them.

HCP indicated more often misinformation (n=19, 9%) followed by patient's dependency (n=16, 7%) and then patient's cognitive-behavioral changes (n=14, 6%).

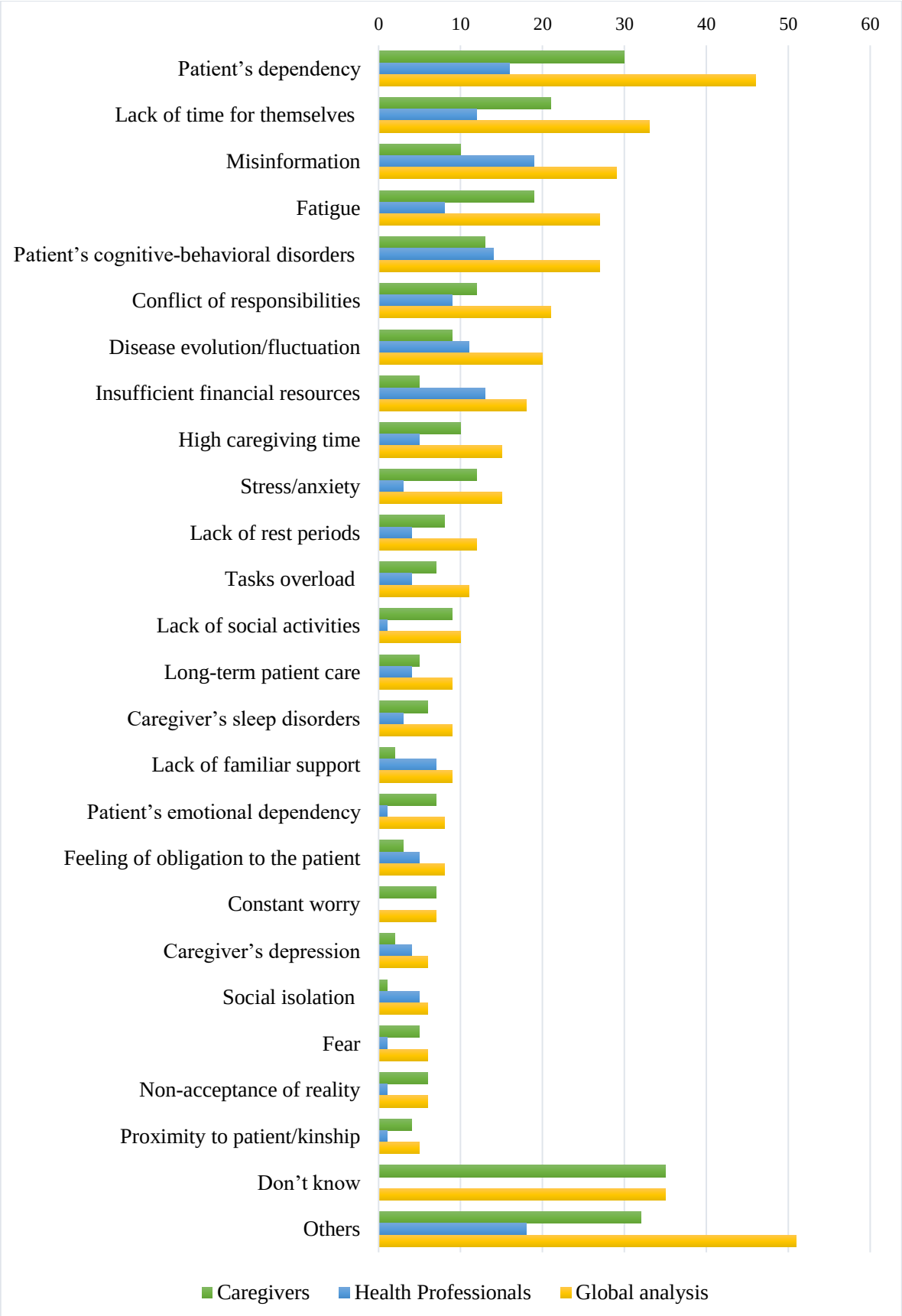

Fig.1.: Frequencies (n) of risk factors for caregiver's burden, mentioned by the participants.

Participants were given a list of potential risk factors for caregivers' burden and asked to rate each one's influence on a 5-point Likert scale. The factors that, in participants' opinion, contribute most to the burden of caregivers are listed below and discriminated in table 2.

Patient's dependence on daily activities

Global analysis (CG and HCP): mean score of 4,5±1,0, representing a moderate to high impact.

CG: mean score of 4,2±1,2, representing a moderate impact.

HCP: mean score of 5,0±0,2, representing a high impact.

A subgroup analysis based on the BI score was performed:

CGs caring for more dependent patients (BI≤55) (n=47)*:* mean score of 3,8±1,4, representing a little to moderate impact.

CGs caring for less dependent patients (BI≥60) (n=51)*:* mean score of 4,7±0,7, representing a moderate to high impact.

Behavioral changes

Global analysis (CG and HCP): mean score of 4,5±0,9, representing a moderate to high impact.

CG: mean score of 4,1±1,0, representing a moderate impact.

HCP: mean score of 4,9±0,4, representing a moderate to high impact.

Humor changes

Global analysis (CG and HCP): mean score of 4,3±0,9, representing a moderate impact.

CG: mean score of 4,1±1,0, representing a moderate impact.

HCP: mean score of 4,7±0,6, representing a moderate to high impact.

Falls

Global analysis (CG and HCP): mean score of 4,3±1,0, representing a moderate impact.

CG: mean score of 4,1±1,2, representing a moderate impact.

HCP: mean score of 4,6±0,6, representing a high impact.

Lack of social and leisure time

Global analysis (CG and HCP): mean score of 4,2±1,1, representing a moderate impact.

CG: mean score of 3,9±1,3, representing a little to moderate impact.

HCP: mean score of 4,7±0,5, representing a moderate to high impact.

A subgroup analysis based on occupational status was performed:

Unemployed and retired CGs (n=39)*:* mean score of 3,7±1,4, representing a little to moderate impact.

Full-time employed CGs (n=54): mean score of 3,9±1,2, representing a little to moderate impact.

Part-time employed CGs (n=7): mean score of 4,4±0,7, representing a moderate impact.

Financial problems

Global analysis (CG and HCP): mean score of 4,2±1,2, representing a moderate impact.

CG: mean score of 3,7±1,4, representing a little to moderate impact.

HCP: mean score of 4,9±0,3, representing a moderate to high impact.

A subgroup analysis based on self-perceived financial status was performed:

CGs with no economic difficulties: mean score of 4,5±0,7, representing a moderate to high impact.

CGs with economic difficulties (capable of covering normal expenses but unable to cover extra expenses; and with difficulty covering normal expenses): mean score of 4,3±0,9, representing a moderate impact.

A subgroup analysis based on occupational status was performed:

Unemployed and retired CGs (n=39)*:* mean score of 3,4±1,4, representing a little impact.

Full-time employed CGs (n=54): mean score of 3,8±1,4, representing a little to moderate impact.

Part-time employed CGs (n=7): mean score of 4,4±0,7, representing a moderate impact.

Lack of social and economic support

Global analysis (CG and HCP): mean score of 4,2±1,2, representing a moderate impact.

CG: mean score of 3,7±1,5, representing a little to moderate impact.

HCP: mean score of 4,9±0,5, representing a moderate to high impact.

Time since diagnosis

Global analysis (CG and HCP): mean score of 4,0±1,1, representing a moderate impact.

CG: mean score of 3,6±1,2, representing a little to moderate impact.

HCP: mean score of 4,5±0,6, representing a moderate to high impact.

Subgroup analyses, based on the patient's diagnosis, were performed for all variables mentioned above. No differences were found.

Table 2: Rate of impact of possible risk factors, using a 5-point scale. (1= None; 5= High) (<2% missing data)

Risk factors (Mean; SD)	Global	CGs	HCPs
Patient's dependence on daily activities	4,5 ± 1,0	4,2 ± 1,2	5,0 ± 0,2
Behavioral changes	4,5 ± 0,9	4,1 ± 1,0	4,9 ± 0,4
Falls	4,3 ± 1,0	4,1 ± 1,2	4,6 ± 0,6
Humor changes	4,3 ± 0,9	4,1 ± 1,0	4,7 ± 0,6
Financial problems	4,2 ± 1,2	3,7 ± 1,4	4,9 ± 0,3
Lack of social and leisure time	4,2 ± 1,1	3,9 ± 1,3	4,7 ± 0,5
Lack of social and economic support	4,2 ± 1,3	3,7 ± 1,5	4,9 ± 0,5
Time since diagnosis	4,0 ± 1,1	3,6 ± 1,2	4,5 ± 0,6
Number of concomitant diseases	4,0 ± 1,3	3, 6 ± 1,4	4,5 ± 0,7

Lack of information about disease	3,9 ± 1,2	3,5 ± 1,3	4,3 ± 0,8
Patient's age when diagnosed	3,8 ± 1,1	3,5 ± 1,1	4,2 ± 0,7
Access to specialists	3,7 ± 1,2	3,4 ± 1,4	4,1 ± 0,7
Access to support groups and/or patients associations	3,7 ± 1,4	3,3 ± 1,5	4,2 ± 1,0
Number of daily medication intakes	3,6 ± 1,2	3,6 ± 1,3	3,8 ± 1,0
Number of monthly visits to the ER	3,4 ± 1,5	2,8 ± 1,7	4,3 ± 0,8
Number of monthly rehabilitation sessions	3,4 ± 1,3	3,1 ± 1,5	3,7 ± 0,9
Educational level	3,3 ± 1,3	2,8 ± 1,3	3,9 ± 0,9
Caregiver's gender	2,7 ± 1,4	2,4 ± 1,5	3,0 ± 1,2

Risk minimization strategies

Globally, the three most frequently mentioned risk minimization strategies (Fig. 2) were socioeconomic support (n=122, 24%), followed by diseases literacy (n=52, 10%) and access to specialized care (n=50, 10%).

Considering only the CGs' group, the three most cited strategies were socioeconomic support (n=54, 18%), caregivers' free time (n=31, 10%) and psychological support (n=26, 9%).

For HCP these were the socioeconomic support (n=68, 31%), access to specialized care (n=35, 16%) and health literacy (n=34, 15%).

The strategies HCPs most frequently recommended (Fig. 3) in clinical routine were promotion of caregiver's free time (n=44, 20%), family support for tasks division (n=37, 17%) and diseases' literacy (n=34, 16%), specifically to be more informed about disease progression and patient care.

According to 64% (n= 46) of HCPs, acceptance rate of these recommendations by the CGs are less than 50%. The most frequently mentioned reasons for refusal were CG's sense of responsibility or obligation towards the patient (n=15, 21%), scarce financial resources (n=10, 14%) and lack of a support network (n=9, 13%).

Caregivers' viewpoint on institutionalization

Sixty-one percent of CGs (n=61) claimed to need more help with caregiving tasks where 74% (n=74) said getting more help would avoid or delay patients' institutionalization. Socioeconomic support and access to specialized care (n=12, 16% for both) are the help they say it's needed the most.

On institutionalization perspectives, 58% of CGs (n=58, 58%) think it would prevent burden while 23% said they had already resorted to this type of help (n=23, 23%).

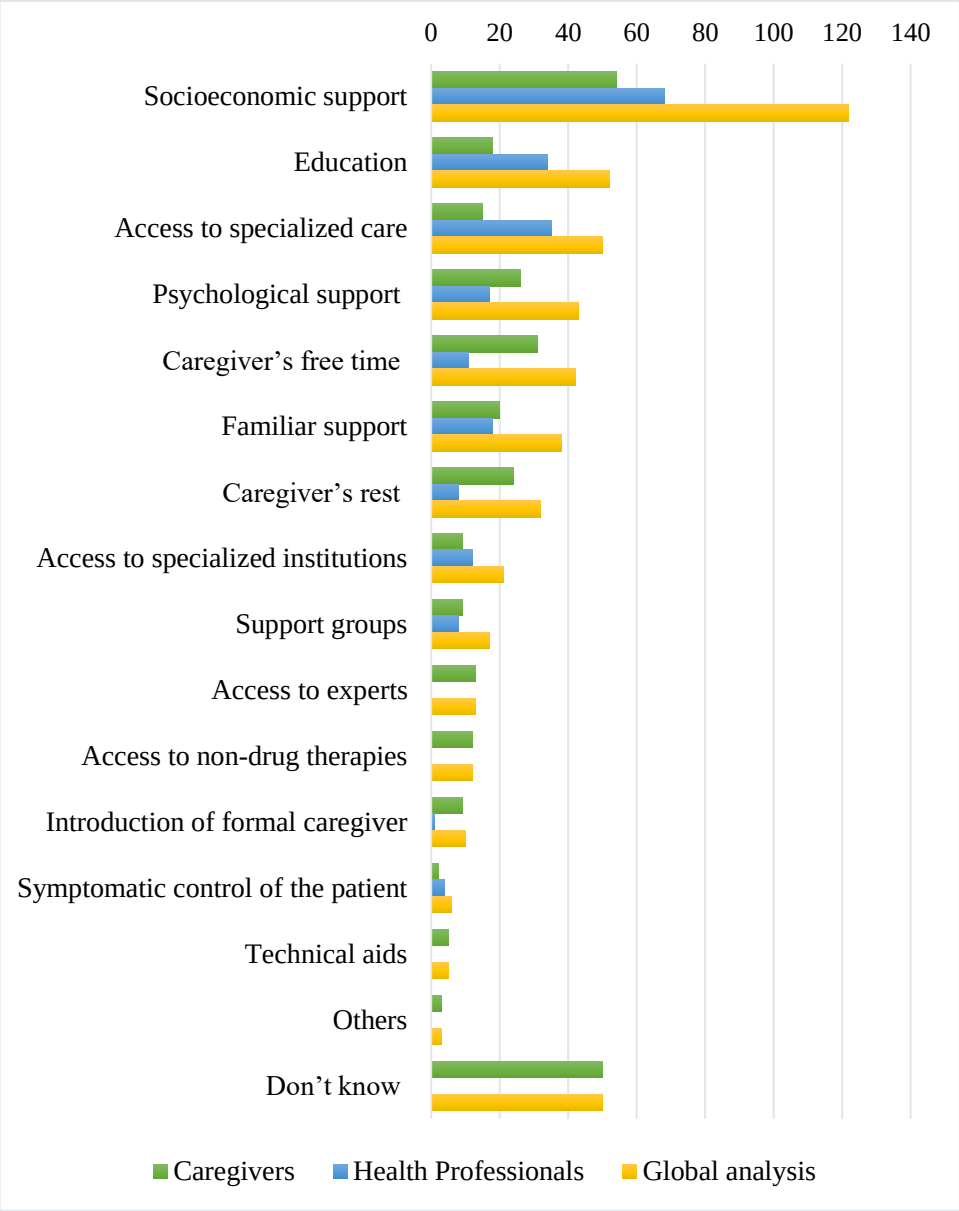

Fig. 2.: Frequencies (n) of relevant minimization strategies mentioned by the participants.

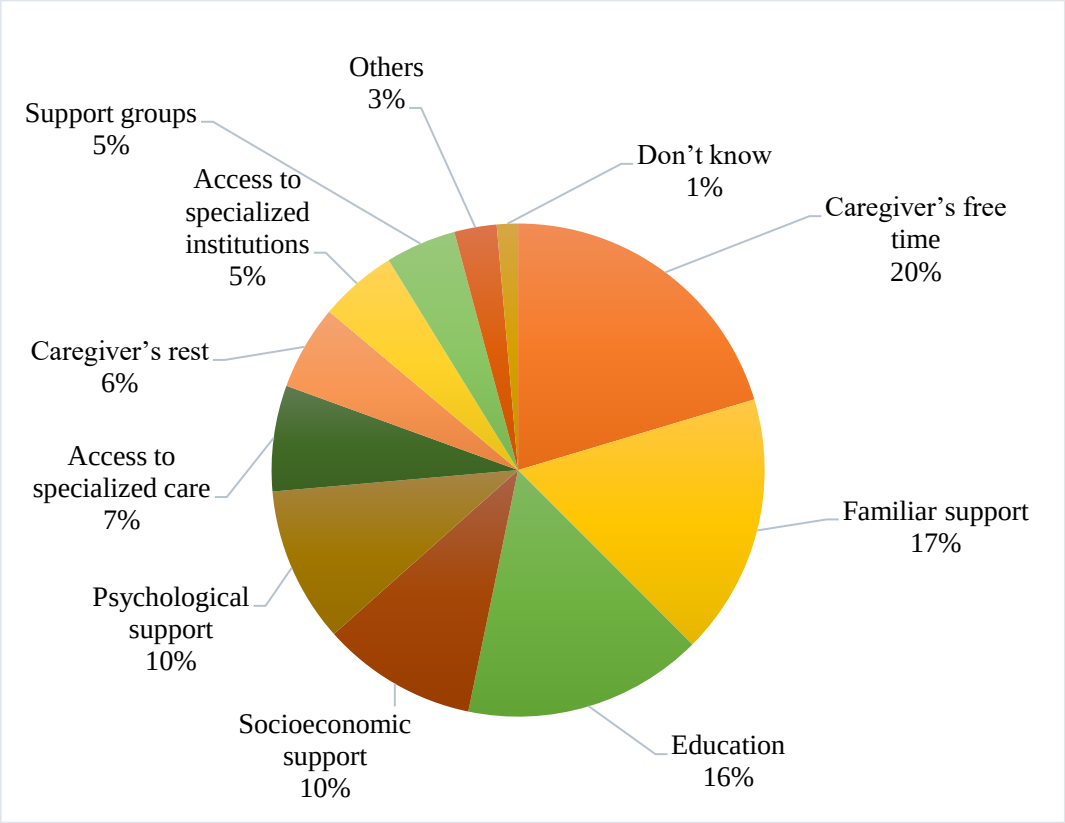

Fig. 3.: Frequencies (%) of most frequently suggested strategies by healthcare professionals.

The concept of caregiver's burden

Globally, the most cited terms mentioned as synonym of caregivers' burden (Fig. 4) were fatigue (n=141, 27%), depression (n=43, 8%) and anxiety (n=19, 4%).

For CGs the most related terms were fatigue (n=80, 27%), depression (n=25, 8%) and stress (n=11, 4%), while for HCPs were fatigue (n=61, 28%), depression (n=18, 8%), anxiety, dependency and lack of support (n=9, 4% for each).

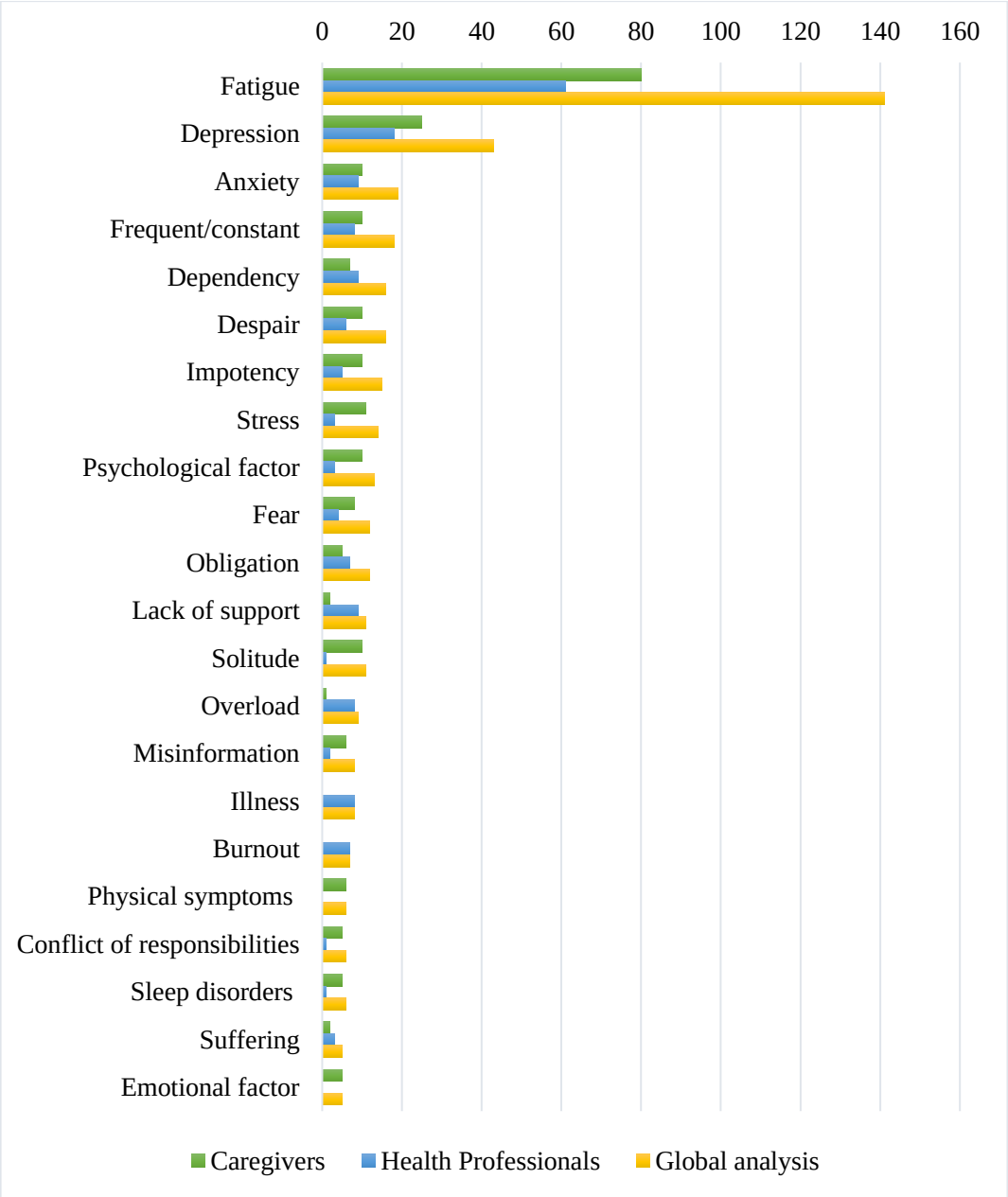

Fig. 4.: Terms for the concept of burden mentioned by the participants.

Assessment of caregivers' burden

Over the past six months, 71% (n=51) of HCPs assessed caregiver's burden in less than half of their CGs. The method used was the clinical interview (n=44, 61%). No clinical scales or patients reported outcomes were mentioned.

DISCUSSION

The 172 study participants had a mean of years caring/working with NDD ranging between the 8-10 years. Although the spouses represent an important percentage (n=38, 38%), the children were the largest group among CGs (n=44, 44%). Globally, patient's dependency (n=46, 9%) and lack of time for the CG (n=33, 6%) were the two factors most consistently cited as risk factors for caregiver burden. The three most frequently mentioned risk minimization strategies were socioeconomic support (n=122, 24%), followed by diseases literacy (n=52, 10%) and access to specialized care (n=50, 10%). All HCPs (n=72, 100%) and majority of CG (n= 90, 90%) associate NDD with caregiver's burden.

Risk factors

Based on the results, the most listed factors seem to comprehend both patient's characteristics and caregiver's-related factors.

While the high caregiving time, economical and psychological factors and the lack of social support are factors present in many other diseases (Adelman et al., 2014; Byun & Evans, 2015; Gabriel, 2019; Liu et al., 2020; Riffin, Van Ness et al., 2019; Suksatan et al., 2022), the presence of both motor and non-motor symptoms, as well as the prolonged duration of the advance and late stages of the disease, seem to be aspects particularly prone to cause caregiver burden in NDD (Santos-García & de la Fuente-Fernández, 2015).

High caregiving time and patient dependency are both well-known risk factors for dementia and PD CGs (Juneja et al., 2020; Lloyd et al., 2019; Macchi et al., 2020; Santos-García & de la Fuente-Fernández, 2015; Waligora et al., 2019). Our findings indicated that one of the most frequently cited factors for CGs was a lack of free time. This can be attributed to the fact that caregiving is typically provided by close family members who frequently live with the patient (Liu et al., 2020). This close proximity and shared living space extend daily caregiving time and cause a conflict between their personal lives and caring responsibilities, making it challenging to find time for social activities and self-care (Liu et al., 2020; Qutub et al., 2014).

To HCPs cognitive-behavioral changes are one of the most important contributing factors. This goes in line with the published evidence on NDD, where the presence of symptoms like apathy, agitation, irritability, anxiety, and sleep disturbances is associated with higher levels of burden, due to their direct impact on the CGs' perceived stress and depressive symptoms

(Hiseman & Fackrell, 2017; Juneja et al., 2020; Pinyopornpanish et al., 2021; Santos-García & de la Fuente-Fernández, 2015; Waligora et al., 2019).

Not all of the most cited factors by CGs are among those rated with the highest score on the Likert-scales. Behavioral and mood changes, and falls were rated has having a high impact for caregiver's burden and were not referred spontaneously by the CGs. We believe that this discrepancy in response may be explained by the fact that CGs initially cite factors that they relate to and that directly affect them; only when presented with additional factors (more related to patients and that indirectly may affect them), do they consider their relevance and recognize their potential impact on burden as well. This attests the lack of knowledge CGs report.

HCPs and CGs who don't experience the specific problem attributes a higher impact to the factor than those who experience in firsthand. We think there could be two reasons for this phenomenon. On the one hand, the fear of the unknown is eliminated because it is something they already experience in real life rather than a hypothetical factor. On the other hand, caregivers may become accustomed to these factors and undervalue the effect they have on their own wellbeing. HCPs should be aware of this and recommend actions to lessen their potential overload.

Other factors identified in previous studies did not emerge in our results. Gender, age and physical and psychological well-being of the CG have been reported (Juneja et al., 2020; Macchi et al., 2020; Perez et al., 2022; Santos-García & de la Fuente-Fernández, 2015; Vescovelli & Ruini, 2022; Waligora et al., 2019). Younger and female CGs seem to be at higher risk of burden (Opara, Jaracz, & Brola, 2012), our sample did not give relevance to gender or age, however, majority of our sample were women in their working age, which could bias the results. Ethnicity has also been identified as a factor in cancer populations as well as dementia CGs, however they were not mentioned in our survey (Fenton et al., 2022; Waligora et al., 2019).

Minimization strategies

The identified minimization strategies are consistent with the risk factors listed and with the intervention CGs claim to be needed. Socioeconomic support appears as the most relevant strategy. CGs also reinforced CGs' free time and psychological support while HCPs emphasized specialized care and education.

Psychological support has been proved to decrease levels of burden on dementia CGs. Emotion and problem-focused coping strategies seem to reduce the impact of psychological stressors and, as a result, the perceived burden, whereas dysfunctional procedures frequently adopted (unconsciously) by CG (such as denial or self-blaming) may raise burden levels (Kazemi et al., 2021; Lloyd et al., 2019; Monteiro et al., 2018). Studies in stoke and cancer showed that referring CGs to specialized professionals improves their self-efficacy on symptoms and stress management and mitigates burden (Hendrix et al., 2017; Ugur & Erci, 2019).

Other non-pharmacological therapies were identified by the CGs but not by HCPs. There is little evidence on non-pharmacological therapies and their impact on burden relief. A study on an occupational therapy program for dementia patients resulted in reduced dependency on ADL and an improvement of neuropsychiatric symptoms, which had a positive effect on CGs' burden (de Oliveira et al., 2019). Despite the lack of evidence, non-pharmacological therapies are well established interventions for improving the functional and cognitive-behavioral performance of NDD patients, components already reported as having a high impact on CGs' risk of developing burden. Higher functionality implies less dependency on ADL and consequently less CGs' time required (Byun & Evans, 2015). Future studies should explore this topic.

The differences between HCPs' and CGs' responses seem to complement each other. While CGs focus on direct strategies to lessen their stress, HCPs prioritize indirect strategies that target the source of the burden. We think that a recommendation plan should incorporate both, i.e., some interventions that are directly focused on the CG and others that target patient's overall health, thereby indirectly easing the burden on caregivers (Lindeza et al., 2020).

HCPs' clinical recommendations are consistent with the CGs' previously identified needs. While HCPs recognize the relevance of strategies targeting the source of burden, it seems that in their practice, suggestions are made on interventions that are easy to apply by the CGs and less dependent on external factors. Other possible explanation is that this topic may only be addressed at later stages, when CG's signs of exhaustion are already present, at which point some strategies (e.g., disease literacy) may be ineffective.

Acceptance rates of suggested strategies seems to be low, with primary justification being the sense of duty to the patient. A previous study on dementia identified self-sacrifice as a potential barrier to CGs' self-management (Waligora et al., 2019). We did not explore CGs' views on this topic in our study, however our results show the need of further investigation and

the importance of not only raising awareness of the population on possible health risks CGs are susceptible to but also of educating CGs for them to allow themselves to receive help.

Although 58% (n=58) of the CG believe that admitting the patient in a nursing home may help prevent burden, only 23% (n=23) of the CG's used this strategy. Caregiver's burden increases patients' propensity to early institutionalization (Krutter et al., 2020; Stephan et al., 2015). Although the early institutionalization of the patient is not desirable, admission to nursing homes for short periods can be a good strategy to optimize the patient's well-being and promote the CG rest.

The concept of caregiver's burden

The concept of burden was described using a wide variety of words, which reflects its subjectivity and complexity. According to the formal definition, burden includes three elements: self-perception, a multifaceted strain, and the gradual development (Liu et al., 2020). The fact that participants' word choices reflect the key aspects of the concept suggests that both HCPs and CGs have a solid understanding of the caregivers' burden.

Despite all HCPs believe that caring for a patient with a NDD is associated with caregiver's burden, its assessment in clinical practice is not frequent. Given the impact of caregiver burden on both the patient's and the patient's health, this aspect should not be overlooked by HCPs. For such an assessment to be integrated into the clinical routine, it is necessary to establish who, when and with what instruments should assess the caregiver's exhaustion and which interventions are most appropriate.

Implications for clinical practice and future research

Preventing or minimizing caregiver's burden requires understanding and alertness to the concept and intervening in both the patient and CG.

For an effective approach to caregiver's burden, it seems to be needed the use of strategies targeting the CG (division of tasks and free time, psychological support, providing quality information about diseases), the patient (timely therapeutic adjustments to optimize symptom control and minimize adverse effects of medication, rehabilitation for functional dependency minimization) and both (greater availability and ease of access to community resources that are socially and financially helpful).

Since some strategies may be difficult to implement once levels of exhaustion are high (e.g., education about the disease), HCP should proactively explore potential factors associated with

burden, suggest simple strategies to prevent or minimize its impact and refer to specialized treatment.

CGs seem to show some reluctance following HCP recommendation to lessen burden. Future studies should raise awareness about the fact that the caregiver can also get sick, the associated risks and the importance of prevention. Future research should also clarify how the burden varies with the disease's progression and the most suitable strategies for each stage.

Study limitations

The fact that this was a national survey and the answers mainly collected in the Lisbon region, might limiting the external generalizability of the results. However, since the scarcity of data on this topic, we believe that our findings are important to identify the most suitable approaches for supporting CGs.

CONCLUSIONS

According to our results, the main factors to the burden of the CGs are patient's dependency, CG's lack of free time and misinformation. Its prevention seems to require an early approach focused on the patient-caregiver dyad. Despite being a well-understood concept and a recognized, by HCP and CG, as a problem associated with NDD, much work remains to be done to increase awareness among HCP for the importance of assessing and preventing this problem and among CG regarding the importance of adopting preventive strategies.

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APPENDIX I: CAREGIVERS' SURVEY

Perspetivas dos cuidadores sobre o desgaste do cuidador nas doenças neurodegenerativas

1. Caracterização geral

Por favor, especifique a sua idade: _____

Com que género se identifica?

◯ Feminino

◯ Masculino

◯ Outro. Por favor, indique: _____

Qual o seu nível educacional?

◯ Nunca estudei

◯ Ensino Primário

◯ Ensino Básico

◯ Ensino Secundário

◯ Ensino Pós-secundário (licenciatura, bacharelato, curso profissional)

◯ Ensino Pós-licenciatura (pós-graduação, mestrado, doutoramento)

Qual o seu estado ocupacional?

◯ Empregado a tempo inteiro (trabalho presencial)

◯ Empregado a tempo inteiro (teletrabalho)

◯ Empregado a tempo parcial

◯ Desempregado

◯ Reformado

◯ Outro. Especifique: _____

Como classificaria o seu estado financeiro atualmente?

◯ Sem dificuldade em cobrir despesas habituais e com capacidade para cobrir gastos extra

◯ Sem dificuldade em cobrir despesas habituais, mas incapaz de cobrir gastos extra

◯ Com dificuldade em cobrir despesas habituais

◯ Prefiro não responder

É cuidador de mais do que um doente?

◯ Sim.

◯ Não.

Se respondeu sim na pergunta anterior, por favor especifique a quantas pessoas presta cuidados: _____

<u>Relativamente ao doente que hoje acompanha:</u>

Qual a idade atual do doente: _____

É cuidador de uma pessoa diagnosticada com:

◯ Doença de Alzheimer

◯ Doença de Parkinson

◯ Esclerose Lateral Amiotrófica

◯ Ataxia de Friedreich

◯ Paraparésia Espástica

◯ Doença de Huntington

◯ Outra. Especifique: _____

Em que ano acha que se iniciou a doença (início de sintomas/queixas ou sinais da doença)? _____

Qual a sua relação/parentesco com o doente?

◯ Esposa/esposo

◯ Filha/filho

◯ Irmã/irmão

◯ Mãe/pai

◯ Sobrinha/sobrinho

◯ Amiga/o

◯ Vizinha/o

◯ Outra. Especifique: _____

Vive com o doente?

◯ Sim

◯ Não

Quantas horas por dia dedica a cuidar com o doente? _____

Há quantos anos é cuidador do doente? _____

Quão dependente nas atividades da vida diária está, o doente de quem cuida?

Escolha a opção que mais corresponde à capacidade atual do doente. (Escala de Barthel, traduzida por Araújo (2007))

Evacuar	Transferências
◯ incontinente (ou necessidade de clisters) ◯ episódios ocasionais de incontinência (uma vez por semana) ◯ continente (não apresenta episódios de incontinência)	◯ incapaz – não tem equilíbrio ao sentar-se ◯ grande ajuda (uma ou duas pessoas), consegue sentar-se ◯ pequena ajuda (verbal ou física) ◯ independente
Urinar	Mobilidade
◯ incontinente ou algaliado ◯ episódios ocasionais de incontinência (máximo uma vez em 24 horas) ◯ continente (por mais de 7 dias)	◯ imobilizado ◯ independente na cadeira de rodas ◯ anda com ajuda de uma pessoa (verbal ou física) ◯ independente (pode usar qualquer auxiliar, ex.: bengala)

Higiene pessoal ◯ necessita de ajuda com o cuidado pessoal ◯ independente no barbear, dentes, rosto e cabelo	Vestir-se ◯ dependente ◯ necessita de ajuda, mas faz metade sem ajuda ◯ independente (incluindo botões, fechos e atacadores)
Ir à casa de banho (uso de sanitário) ◯ dependente ◯ necessita de ajuda, mas consegue fazer algumas coisas sozinho ◯ independente (senta-se, levanta-se, limpa-se e veste-se sem ajuda)	Escadas ◯ incapaz ◯ necessita de ajuda (verbal, física) ou supervisão ◯ independente (subir/descer, com apoio do corrimão ou dispositivos)
Alimentação ◯ incapacitado ◯ precisa de ajuda para cortar, passar manteiga, etc. ou dieta modificada ◯ independente	Banho ◯ dependente ◯ independente

As questões seguintes remetem a como se sente enquanto cuidador.

Escolha a opção que mais corresponde à sua situação atual. ("Zarit Burden Interview (ZBI)", traduzida por Sequeira (2010)

	Nunca	Quase nunca	Às vezes	Muitas vezes	Quase sempre
Sente que o seu familiar solicita mais ajuda do que aquela que realmente necessita?					
Considera que devido ao tempo que dedica ao seu familiar já não dispõe de tempo suficiente para as suas tarefas?					
Sente-se tenso/a quando tem de cuidar do seu familiar e ainda tem outras tarefas por fazer?					

Sente-se envergonhado(a) pelo comportamento do seu familiar?					
Sente-se irritado/a quando está junto do seu familiar?					
Considera que a situação atual afeta de uma forma negativa a sua relação com os seus amigos/familiares?					
Tem receio pelo futuro destinado ao seu familiar?					
Considera que o seu familiar está dependente de si?					
Sente-se esgotado quando tem de estar junto do seu familiar?					
Vê a sua saúde ser afetada por ter de cuidar do seu familiar?					
Considera que não tem uma vida privada como desejaria devido ao seu familiar?					
Pensa que as suas relações sociais são afetadas negativamente por ter de cuidar do seu familiar?					
Sente-se pouco à vontade em convidar amigos para o(a) visitarem devido ao seu familiar?					
Acredita que o seu familiar espera que você cuide dele como se fosse a única pessoa com quem ele(a) pudesse contar?					
Considera que não dispõe de economias suficientes para cuidar do seu familiar e para o resto das despesas que tem?					
Sente-se incapaz de cuidar do seu familiar por muito mais tempo?					
Considera que perdeu o controle da sua vida depois da doença do seu familiar se manifestar?					
Desejaria poder entregar o seu familiar aos cuidados de outra pessoa?					
Sente-se inseguro acerca do que deve fazer com o seu familiar?					
Sente que poderia fazer mais pelo seu familiar?					
Considera que poderia cuidar melhor do seu familiar?					

Em geral sente-se muito sobrecarregado por ter de cuidar do seu familiar?					

2. Conceito de desgaste do cuidador

O que lhe vem à cabeça quando ouve falar em "desgaste do cuidador"? Diga-nos três palavras que associe a este conceito:

1. _____
2. _____
3. _____

Desgaste do cuidador é definido como o stress ou sobrecarga, multifatorial, sentido por uma pessoa que cuida de alguém doente, fisicamente incapaz ou idoso. Pode levar a problemas de saúde do cuidador e a uma pobre prestação de cuidados ao doente.

Pensa que a doença do seu familiar pode provocar uma situação de desgaste do cuidador?

◯ Sim

◯ Não

Consegue identificar três fatores que ache que contribuem para o desgaste do cuidador?

1. _____
2. _____
3. _____

No seu caso, quantos dos fatores que identificou na pergunta anterior se aplicam a si? _____

3. Fatores contribuintes para o desgaste do cuidador

Cuidados prolongados, recursos financeiros insuficientes e conflito entre as responsabilidades de cuidar e outras responsabilidades, por exemplo familiares ou laborais, foram identificados como fatores associados a desgaste do cuidador.

Gostaríamos que ponderasse sobre alguns fatores e como eles podem ou não estar relacionados com o desgaste do cuidador. Avalie o seu impacto de “Nenhum” a “Elevado”

	Nenhum	Mínimo	Pouco	Moderado	Elevado
Género do cuidador					

Idade do doente quando diagnosticado					
Tempo desde diagnóstico					
Número de outras doenças presentes					
Dependência do doente nas atividades diárias					
Quedas					
Acesso a um especialista					
Problemas financeiros					
Alterações comportamentais					
Alterações de humor					
Falta de informação acerca da doença					
Número de visitas por mês às urgências					
Número de sessões de reabilitação por mês					
Número de tomas de medicação por dia					
Nível de educação					
Falta de tempo social e de lazer					
Falta de ajudas sociais e económicas					
Acesso a grupos de apoio e/ou associações de doentes					

4. Estratégias de minimização de risco de desgaste do cuidador

Na sua opinião, o que poderá prevenir ou reduzir o desgaste do cuidador? Nomeie três fatores.

1. _____
2. _____
3. _____

A quais dos fatores que mencionou na questão anterior tem acesso? _____

Enquanto cuidador, sente que necessita de ajuda/ mais ajuda no cuidado ao doente?

◯ Não

◯ Sim.

Se respondeu sim à questão anterior, que ajudas considera que necessita? _____
_____
_____

O acesso às ajudas que menciona poderá atrasar ou evitar a necessidade de colocar o seu familiar num lar ou instituição semelhante?

◯ Sim

◯ Não

Na sua opinião, colocar o seu familiar num lar ou instituição semelhante por um período curto pode ser uma forma de evitar o desgaste do cuidador?

◯ Sim

◯ Não

Alguma vez recorreu a este tipo de ajudas?

◯ Sim

◯ Não

O questionário chegou ao fim.

Agradecemos a sua disponibilidade e vontade em participar no estudo. Quaisquer questões ou sugestões, contacte via email através do endereço: ***desgastedocuidador@outlook.com***.

APPENDIX II: HEALTHCARE PROFESSIONALS' SURVEY

Perspetivas dos profissionais de saúde sobre o desgaste do cuidador nas doenças neurodegenerativas

1. Caracterização geral

Por favor, especifique a sua idade: _____

Com que género se identifica?

◯ Feminino

◯ Masculino

◯ Outro. Por favor, especifique: _____

Por favor, especifique a sua profissão: _____

Há quanto tempo trabalha com doentes neurodegenerativos? Especifique em anos. _____

Por favor, especifique o seu contexto laboral (pode indicar mais do que um):

□ Hospital

□ Clínica de ambulatório

□ Unidade de cuidados primários

□ Unidade de cuidados continuados

□ Serviços domiciliário

□ Outros. Especifique: _____

2. Conceito de desgaste do cuidador

O que lhe vem à cabeça quando ouve falar em "desgaste do cuidador"? Diga-nos três palavras que associe a este conceito:

1. _____
2. _____
3. _____

Desgaste do cuidador é definido como a tensão ou carga, multifatorial, sentida por uma pessoa que cuida de alguém doente, fisicamente incapaz ou idoso. Pode levar a problemas de saúde do cuidador e a uma pobre prestação de cuidados ao doente.

Na sua opinião, os cuidadores de pessoas com doença neurodegenerativa podem sofrer de desgaste ou sobrecarga do cuidador?

◯ Sim

◯ Não

Durante as suas consultas, avalia o desgaste do cuidador? Se sim, como faz habitualmente esta avaliação? (pode indicar mais do que um)

□ Não avalio habitualmente este parâmetro nas minhas consultas

□ Avalio através de entrevista clínica

□ Avalio através de instrumentos específicos para este fim.

Se respondeu que avalia o desgaste do cuidador usando instrumentos específicos, por favor especifique quais: _____

Nos últimos 6 meses, em que percentagem dos seus utentes e cuidadores abordou este tópico?

◯ 0-25%

◯ 26-50%

◯ 51-75%

◯ 76-100%

Nos últimos 6 meses, de acordo com o seu melhor juízo clínico qual a percentagem de cuidadores que segue que estava numa situação de exaustão?

◯ 0-25%

◯ 26-50%

◯ 51-75%

◯ 76-100%

3. Fatores contribuintes para o desgaste do cuidador

Quais os três fatores que, na sua opinião, mais contribuem para o desgaste do cuidador?

1. _____
2. _____
3. _____

Cuidados prolongados, recursos financeiros insuficientes e conflito entre as responsabilidades de cuidar e outras responsabilidades, por exemplo familiares ou laborais, foram identificados como fatores associados a desgaste do cuidador.

Gostaríamos que ponderasse sobre alguns fatores e como eles podem ou não estar relacionados com o desgaste do cuidador. Avalie o seu impacto de "Nenhum" a "Elevado"

	Nenhum	Mínimo	Pouco	Moderado	Elevado
Género do cuidador					
Idade do doente quando diagnosticado					
Tempo desde diagnóstico					
Número de outras doenças presentes					
Dependência do doente nas atividades diárias					
Quedas					
Acesso a um especialista					
Problemas financeiros					
Alterações comportamentais					
Alterações de humor					
Falta de informação acerca da doença					
Número de visitas por mês às urgências					
Número de sessões de reabilitação por mês					
Número de tomas de medicação por dia					

Nível de educação					
Falta de tempo social e de lazer					
Falta de ajudas sociais e económicas					
Acesso a grupos de apoio e/ou associações de doentes					

4. Estratégias de minimização de risco de desgaste do cuidador

Na sua opinião, o que poderá prevenir ou reduzir o desgaste do cuidador? Nomeie três fatores.

1. _____
2. _____
3. _____

Por favor, especifique três estratégias que mais frequentemente sugere aos cuidadores dos seus doentes:

1. _____
2. _____
3. _____

Qual a taxa (aproximada) de aceitação das recomendações por parte dos cuidadores?

◯ 0-25%

◯ 26-50%

◯ 51-75%

◯ 76-100%

Qual a principal razão para a não aceitação das recomendações sugeridas?

_____

O questionário chegou ao fim.

Agradecemos a sua disponibilidade e vontade em participar no estudo. Quaisquer questões ou sugestões, contacte via email através do endereço: ***desgastedocuidador@outlook.com***.

APPENDIX III: INFORMED CONSENT

Perspetivas dos cuidadores e profissionais de saúde sobre o desgaste do cuidador nas doenças neurodegenerativas

Informação aos participantes

O desgaste do cuidador é um problema associado à prestação de cuidados prolongada a pessoas doentes, incapacitadas ou idosas. Afeta a saúde e a qualidade de vida do doente e do cuidador. As doenças neurodegenerativas parecem estar fortemente associadas ao desgaste do cuidador.

Gostaríamos de o convidar a participar num questionário anónimo que tem como objetivo explorar as perspetivas de profissionais de saúde e cuidadores de pessoas com doença neurodegenerativa sobre o desgaste do cuidador.

Ao aceitar participar, ser-lhe-á pedido que preencha um questionário que aborda o conceito de desgaste do cuidador, os fatores que contribuem para o seu aparecimento e aqueles que o podem minimizar. O preenchimento do questionário não esperamos que demore mais que 10 minutos.

Caso decida não participar, quer antes de iniciar o questionário, quer a meio, não será prejudicado. Para tal, basta fechar o questionário sem submeter as respostas ou, caso preencha em papel, comunicar ao investigador a sua decisão. Todos os seus dados pessoais que tenham sido recolhidos até ao momento serão apagados de forma definitiva.

Para quaisquer dúvidas ou questões, pode contactar a equipa via e-mail através do seguinte contacto: *desgastedocuidador@gmail.com*. A equipa tratará de responder com a maior celeridade possível.

Agradecemos desde já a sua colaboração e vontade em participar.

Consentimento informado para o participante

O/A Sr./Sra. _____ aceita participar no estudo intitulado "Perspetivas dos cuidadores e profissionais de saúde sobre o desgaste do cuidador nas doenças neurodegenerativas", após ter sida transmitida a informação aos participantes e clarificadas todas as dúvidas.

Data___/____/_____ Hora ____:____ Data___/____/_____Hora ____:____

Assinatura do Investigador: Assinatura do Participante:

_____ _____

Consentimento informado para o centro de investigação

O/A Sr./Sra. _____ aceita participar no estudo intitulado “Perspetivas dos cuidadores e profissionais de saúde sobre o desgaste do cuidador nas doenças neurodegenerativas”, após ter sida transmitida a informação aos participantes e clarificadas todas as dúvidas.

Data___/____/_____ Hora ____:____ Data___/____/_____Hora ____:____

Assinatura do Investigador: Assinatura do Participante:

_____ _____