

# Reducing the burden of caregivers in Huntington's by using an online interventional neuropsychological approach: a pilot study

Tatiana Henrique Santos<sup>1#</sup>, Fernanda Naomi Pantaleão<sup>2,3</sup>, Tatiana Namura Machado<sup>2</sup>,  
Leonardo de Oliveira Luiz<sup>2</sup>, Tamine T.C. Capato<sup>4,5#</sup>

**ABSTRACT:** Huntington's disease (HD) is a hereditary, neurodegenerative disease characterized by motor, cognitive, and behavioral issues. As the disease progresses, people become dependent on their caregivers leading to a significant burden. There is a lack of effective neuropsychological intervention to support this population. **Objective:** To develop an online neuropsychological intervention and evaluate its effects in decreasing the HD caregiver burden. **Methods:** This qualitative pilot study was conducted online during the COVID-19 pandemic in Brazil. We selected a convenience sample of five informal caregivers of HD patients (mean 46.2 years old). At baseline, participants were assessed via an individual online neuropsychology interview/screening, covering demographic data. Subsequently, we conducted 20 online 90-minute sessions of the psychological consultation over 12 months. Each session was structured in three stages: 1) Welcoming; 2) Breathing and mindfulness practice; and 3) Discussion of themes about the group's needs based on the main complaints. A second intervention assessment was applied. **Results:** None of the caregivers were provided with details about HD at the time of diagnosis and later care. The necessity to care for a person with a rare genetic disease was added to caregivers' already-existing working routine and home services, causing a symptom of overload. After the neuropsychological intervention, all participants reported feeling less burdened by caring, improved self-care and conflict resolution with the person with HD through expanding behavioral repertoire focused on emotions and communication. **Conclusion:** Online neuropsychologic intervention can reduce the burden of HD caregivers. More comprehensive studies should investigate these findings.

**Keywords:** Huntington Disease; Caregiver Burden; Patient Care Team; Rehabilitation; Telerehabilitation.

## Reduzindo a sobrecarga dos cuidadores na doença de Huntington usando uma abordagem neuropsicológica interativa *online*: um estudo piloto

**RESUMO:** A doença de Huntington (DH) é hereditária e neurodegenerativa, caracterizada por problemas motores, cognitivos e comportamentais. À medida que avança, os pacientes dependem cada vez mais de cuidadores, gerando uma sobrecarga significativa. Há uma carência de intervenções neuropsicológicas eficazes para apoiar esta população. **Objetivo:** Desenvolver uma intervenção neuropsicológica *online* e avaliar seus efeitos na redução da sobrecarga do cuidador em DH. **Métodos:** Este estudo piloto qualitativo ocorreu *online*, durante a pandemia de COVID-19 no Brasil. Selecionamos uma amostra de conveniência de cinco cuidadores informais de pacientes com DH (média de 46,2 anos). Inicialmente, realizamos triagens neuropsicológicas *online*, abrangendo dados demográficos e entrevistas. Subsequentemente, conduzimos 20 sessões de 90 minutos ao longo de 12 meses, estruturadas em: 1) acolhimento, 2) prática de respiração e *mindfulness* e 3) discussão das necessidades do grupo com base nas principais queixas. Após a intervenção, realizamos uma segunda avaliação. **Resultados:** Constatamos que os cinco cuidadores não foram adequadamente educados pelos profissionais de saúde sobre a DH após o diagnóstico. A responsabilidade de cuidar da pessoa com DH foi agregada à sua rotina de trabalho e serviços domiciliares, ocasionando um sintoma de sobrecarga. Após a intervenção neuropsicológica *online*, todos os participantes relataram menos sobrecarga relacionada ao cuidado das pessoas com DH, melhoraram o autocuidado e a resolução de conflitos por meio da ampliação do repertório comportamental focado nas emoções e na comunicação. **Conclusão:** A intervenção neuropsicológica *online* pode diminuir a sobrecarga dos cuidadores em DH. Estudos mais abrangentes devem investigar esses resultados.

**Palavras-chave:** Doença de Huntington; Sobrecarga do Cuidador; Equipe de Assistência ao Paciente; Reabilitação; Telerreabilitação.

This study was conducted by the Rehabilitation group of Clínica de Distúrbios do Movimento, Departamento de Neurologia, Universidade de São Paulo.

<sup>1</sup>Associação Brasil Huntington, São Paulo SP, Brazil.

<sup>2</sup>Faculdade de Psicologia, Universidade Presbiteriana Mackenzie, São Paulo SP, Brazil.

<sup>3</sup>Instituto Nacional de Ciência e Tecnologia em Neurociência Social e Afetiva, Conselho Nacional de Desenvolvimento Científico e Tecnológico, São Paulo SP, Brazil.

<sup>4</sup>Clínica de Distúrbios do Movimento, Departamento de Neurologia, Universidade de São Paulo, São Paulo SP, Brazil.

<sup>5</sup>Department of Neurology, Donders Institute for Brain, Cognition and Behavior, Radboud University Medical Centre, Nijmegen, Netherlands.

#Contributed equally.

**Correspondence:** Tamine Teixeira da Costa Capato; Email: taminec@usp.br.

**Disclosure:** The authors report no conflicts of interest.

**Funding:** none.

Received on December 08, 2023; Received in its final form on March 09, 2024; Accepted on March 24, 2024.



## INTRODUCTION

Huntington's disease (HD) is a rare, hereditary, neurodegenerative disease<sup>1</sup> characterized by motor symptoms (chorea), and cognitive and behavioral issues<sup>1,2</sup>. HD symptom management may require a multidisciplinary approach, including pharmacological and non-pharmacological interventions<sup>3</sup>. As the disease progresses, dependency increases significantly for transfers and locomotion<sup>4</sup>. Consequently, functional limitation and immobility increase the caregiver burden<sup>5</sup>. Physiotherapy, speech therapy, and psychology help maintain functionality and quality of life<sup>6</sup>.

We can define the caregiver burden by the effects of the act of caring and the impact on caregivers' perceptions of their overall health (physical, emotional, and social well-being)<sup>7-9</sup>. In Brazil, informal caregivers generally take over the care; most are family members or spouses<sup>10</sup>. These HD caregivers deal daily with a variety of problems like mobility, functionality, feeding (motor disorders), behavioral (depression, apathy, aggression, among others), and cognitive (executive dysfunction)<sup>5,8</sup>. Therefore, the burden of caregivers of people with HD is huge and only a few studies support strategies to improve it.

In studies designed to assess improvement in the burden experienced by family caregivers of individuals with dementia, various types of interventions are highlighted: psychoeducation, leisure and physical activities, cognitive-behavioral approaches (behavioral activation), mindfulness-based interventions, and support groups<sup>11-14</sup>.

Therefore, the objectives of this study were to develop an online neuropsychological intervention for informal HD caregivers and to verify the effect of this intervention to decrease the caregivers' burden.

## METHODS

A convenience sample of five informal caregivers of people with HD was analyzed in this qualitative pilot study. All individuals with HD were genetically confirmed (trinucleotide repeat number  $\geq 39$ ). The inclusion criteria were:

- Be an informal caregiver of a person with HD;
- Not receiving any psychological intervention or support;
- Be on the waiting list for psychotherapy services at ABH (Brazil Huntington's Association); and
- Be available to participate in group sessions.

The study was conducted as part of an ABH initiative started in 2020 to support people with HD and

their families during the most critical phase of the COVID-19 pandemic, in partnership with Mackenzie Presbyterian University. This project was approved by the Ethics Committee of Moriah Hospital (CAEE: 52630221.6.0000.8054).

## Procedures

### Study design

All participants, after signing up for a psychological consultation at ABH, went through the individual screening process. A baseline assessment was conducted via an online interview, and the psychological consultation involved collecting demographic data and information about the primary complaint (Supplementary Material, Appendix A).

The consultations were conducted online using the Google Meet platform. The meetings took place once per week, in the evening, and were conducted by the psychology team which was composed of one psychologist who supervised three Psychology students in their final year of undergraduate school. The assessments and training were supervised by a psychologist who specialized in neurological patients and had clinical experience with HD. Moreover, the three Psychology students who participated in the sessions had received previous training about HD prior to the interventions. They had been trained to be assistants in this project and were continuously supervised throughout the entire study period. The group of participants (caregivers) remained the same, and all of the sessions were conducted by the same professionals during the study period. In total, 20 online sessions, each lasting 90 minutes, were delivered over one year.

### Assessments

The participants were assessed before and after an online physiological intervention. We identified that "burden" was the most common descriptor applicable to all caregivers. Their primary complaints included:

- Fatigue;
- Difficulty dealing with the person with HD;
- Feeling overloaded due to their work; and
- Feeling that their quality of life (QoL) and/or personal life was overloaded because of their caregiving duties.

After each session, we assessed the descriptions of the emotional state and burden of each participant recorded in the session reports. An initial assessment was conducted based on an interview before the start of the sessions, and a final assessment was also made

based on an interview at the 20th post-intervention session. The sessions had pre-defined themes and typically began with an initial question. Subsequent questions were formulated openly during the group sessions and addressed the participants' descriptions of their emotional state and burden (Table 1)<sup>15,16</sup>. We did not collect any quantitative data in this pilot study that would have enabled pre- and post-intervention comparisons. Such data collection is planned for an upcoming study.

### Protocol of the psychological interventions

The interventions were developed from themes that touched on "burden" (e.g., interpersonal relationships, stress, self-observation, and self-care),

strategies to more effectively assist people with HD, and strategies to decrease the burden and improve the caregivers' QoL. All interventions were based on functional analysis following the Functional Analytic Psychotherapy (FAP). This modality of psychotherapy focuses on identifying the function of a behavior in an individual's life<sup>17,18</sup>.

In addition to FAP, we also used the Dialectical Behavior Therapy (DBT) intervention strategies. This form of treatment also stems from the Behavior Analysis. Its biosocial and dialectical purpose is to help individuals modify certain behavioral, emotional, interpersonal, and thinking patterns that are associated with life problems<sup>19</sup>. As stated by DBT, feeling validated is one way to help individuals modify these patterns. Accordingly,

**Table 1.** Description of sessions.

| Session | Theme                                       | Techniques and interventions                                                                                                                                             |
|---------|---------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1       | Presentation                                | Questions about the current context of each participant.                                                                                                                 |
| 2       | Participants' individual history            | Choose a movie genre that represents your personal life and explain why.                                                                                                 |
| 3       | Relationship with the person with HD.       | Questions about people with HD and their relationships with caregivers. How do you feel when caring for these people?                                                    |
| 4       | Self-perception                             | Medicine leaflet set (describe it as a medicine, mentioning dosage, indications, and adverse effects).                                                                   |
| 5       | How do I deal with what I can not change?   | Basic instructions for understanding some HD problems <sup>16</sup> .                                                                                                    |
| 6       | Self-care                                   | Questions focused on the analysis of self-care practices and suggestions for tasks during the recess period of care (insertion of self-care practices into the routine). |
| 7       | Return of sessions after recess             | Questions about routine and current emotional state and during the period without assistance (school recess).                                                            |
| 8       | Maintenance of the therapeutic relationship | Introduction of a new participant. Continuation of questions about the period without assistance and exchange of information about HD.                                   |
| 9       | Formal work and HD                          | Questions about work, time management, and self-care.                                                                                                                    |
| 10      | Session to clarify doubts about HD.         | Explanations about the general and behavioral aspects of HD.                                                                                                             |
| 11      | Support network                             | Questions about support network, sharing feelings, and problem solving.                                                                                                  |
| 12      | Identification and validation of feelings   | Request for reports of situations that generate positive and negative feelings, with consequent recognition and validation of these feelings.                            |
| 13      | Identification and validation of feelings   | Questions about feelings; reading of the fictional story of a wife of a person with HD aimed at helping to identify, discuss, and validate the feelings of others.       |
| 14      | Understanding the cause of feelings         | Recognition of one's own needs and identification of feelings subsequent to them, practice of three of the four steps of NVC <sup>15</sup> .                             |
| 15      | Communication of feelings                   | Practice the four steps of NVC <sup>15</sup> on the previously introduced fictional character.                                                                           |
| 16      | Communication of feelings                   | Practice of the four steps of NVC <sup>15</sup> based on situations brought by the participants.                                                                         |
| 17      | Dealing with stress                         | Body and emotional perception in stressful situations.                                                                                                                   |
| 18      | Tiredness and guilt                         | Questions and discussion about tiredness and guilt related to the relationship with HD care.                                                                             |
| 19      | Self-care                                   | Questions about self-perception and reinforcement about the need to maintain self-care strategies.                                                                       |
| 20      | Closing session                             | Questions about the participants' perception of the therapeutic process and sharing of observed changes.                                                                 |

Abbreviations: HD, Huntington's disease; NVC, Non-violent communication. Notes: Weekly supervisions were conducted after each session. During these supervisions, the activities performed were reviewed, and strategies for the upcoming planned interventions were discussed providing regular monitoring and continuous refinement of therapeutic approaches.

we used DBT to validate the caregiver’s feelings and encourage them to identify when they have their feelings invalidated.

### Structure of the therapy sessions and interventions

Beginning with the first visit, the psychologists established the rules and guidelines of the interventions (e.g., date, time, and 90-minute duration of the sessions). The participants received orientation to the online platform and how to prepare for a session (e.g., they should be in a quiet place, using headphones) and information that confidentiality (personal data, e.g., name, age, address) would be removed prior to using the data in any study). If there was a need, participants received an individual approach; the team of psychologists provided such support until the participant could return to the group session.

The therapy sessions included three phases:

- Phase 1: A welcome after the participant accessed the service link (5 minutes);
- Phase 2: A short (10 minutes) breathing and mindfulness practice; and
- Phase 3: Dialog according to a specific theme (75 minutes).

The mindfulness work, which included meditation practice, was intended to help the participants focus and as a training strategy for intentional self-regulation<sup>20,21</sup>. The breathing and mindfulness techniques were initially used to provide a moment of relaxation during what might otherwise have been a stressful experience for the participants.

Non-violent Communication (NVC) is an interventional strategy based on the observations of feelings and behaviors; it incorporates language and communication skills to promote clearer dialogue and relationships characterized by more respect and attention<sup>15</sup>. The strategy consists of four steps:

- Making observations without judgment;
- Identifying feelings;
- Assuming responsibilities; and
- Making requests. During the five sessions, we worked to address the emotional situations that bothered the participants to help them communicate their needs in a different way, seeking to avoid conflicts.

To assist the participants in the various stages of the NVC, we adopted the strategy of creating a story assembled with specific characteristics from the reports of each of the caregivers so that they could observe situations in their lives indirectly (Supplementary

Material – Appendix B). It was accordingly possible to analyze the feelings, situations, and behaviors present in the caregivers’ daily lives and, later, to formulate coping strategies. Subsequently, another fictional story with the same characters was used to allow caregivers to practice the steps of NVC before using those steps in real life (Supplementary Material – Appendix C).

## RESULTS

Five women participated in the study, with mean age of 46.2 years (standard deviation [SD]±13.5). All participants were caregivers of at least one person with HD. Furthermore, all women had at least one child. The mean age of the caregivers’ children was 23.2 years (SD±15.5). Four of the women were wives of people living with HD. Of those four people, two were also mothers and one was the daughter of a person with HD (Table 2).

None of the caregivers were provided with details about HD at the moment they received the diagnosis. Subsequently, the necessity of caring for a person with a rare genetic disease was added to caregivers’ already-existing work. It is, therefore, not surprising that they stated feeling overloaded and were seeking information about how they could provide care more efficiently.

**Table 2.** Characterization of the participants.

|                                                                                        | Caregiver (n=5) |
|----------------------------------------------------------------------------------------|-----------------|
| Age, years (mean/SD)                                                                   | 46 (13)         |
| Sex, n                                                                                 |                 |
| Female                                                                                 | 5               |
| Education level, n (%)                                                                 |                 |
| Complete elementary school                                                             | 1 (20)          |
| Complete high school                                                                   | 2 (40)          |
| Complete higher education                                                              | 1 (20)          |
| Incomplete higher education                                                            | 1 (20)          |
| Profession, n (%)                                                                      |                 |
| Teacher                                                                                | 1 (20)          |
| Salesperson                                                                            | 3 (60)          |
| Self-employed                                                                          | 1 (20)          |
| Relationship with the patient, n                                                       |                 |
| Spouse                                                                                 | 4               |
| Mother                                                                                 | 2               |
| Child                                                                                  | 1               |
| Previous experience as a caregiver for another person with Huntington’s disease, n (%) | 3 (60)          |
| Children age, years (mean/SD)                                                          | 23 (15)         |

Abbreviations: N, number; SD, standard deviation.

While this study focused on the difficulties and fatigue caused by the act of caring, we also noted issues related to self-perception and self-care. When the participants were asked to talk about themselves, they often brought up aspects of their charge and the frequency and intensity of her necessary care. The participants also presented critical and depreciated perceptions of themselves and their physical and psychological characteristics. The respondents also vocalized misperceptions and/or misunderstandings about some of the behavioral aspects of HD; this situation possibly arose due to the limited dissemination of information about the disease<sup>22</sup>. In light of the needs of the participants—inferred via screenings and literature on the subject—the intervention sought to alleviate their feelings of overwork and resulting state of stress. Our work also aimed to promote self-care and more functional relationships.

Only one caregiver noted that it was difficult or impossible to reconcile care with their own personal and professional life; that situation depended on the stage of HD under their charge. After the online psychological intervention, all five participants reported during the group discussions that they were making use of what they had learned (e.g., breathing techniques and inserting moments of self-care into their daily lives). We also noticed a considerable improvement in the psychological aspects of all participants during the first six months of the intervention.

After 12 months of intervention, all participants reported improvements in their abilities to self-reflect, listen, be welcoming, share their experiences, and provide mutual support. Those abilities, in turn, brought about relief and comfort. After the intervention, the participants reported feeling less burdened by caring for people with HD.

## DISCUSSION

This qualitative pilot study involved an online psychological intervention to reduce the burden experienced by informal caregivers of people with HD. As a result of weekly meetings, the participants reported a greater understanding of their own emotional and relational issues. In addition, it is important to note that this psychological care intervention was carried out in 2021, during the COVID-19 pandemic. Studies have shown that acute periods of the COVID-19 pandemic were linked to an increase in sadness, symptoms of depression and anxiety, and a decreased QoL<sup>23</sup>.

Our results are consistent with those of early studies that noted HD caregivers are often affected by behavioral changes and require concerted cognitive, emotional,

and physical efforts to continue providing care<sup>24</sup>. In addition, difficulties suffered by this population include lack of freedom, stress, anger, anguish, and fatigue<sup>8</sup>. Stress is a common aggravating factor in the daily lives of caregivers; it is mainly linked to the symptoms of the disease itself, the stage of the disease experienced by their charge, and the involvement of the caregiver<sup>7</sup>. Stressful events or circumstances tend to increase feelings of frustration, overload, and lack of support; those circumstances also represent an impediment to achieving goals<sup>25</sup>. Caregivers may also suffer from a self-care deficit; their work might necessarily reduce the amount of attention they can devote to themselves. This situation is important because caregivers must make sure that they do not negatively affect their own physical and emotional well-being; they must appreciate themselves as individuals and recognize their own physical and emotional capabilities. Caregivers are forced to deal with the reality and demands of caring for others<sup>14</sup>. Trials on large numbers of caregivers should be conducted to better understand these findings.

The reduced burden reported by participants (n=5) post-intervention may be explained by several factors. First, we believe that the intervention strategies used in this study provided knowledge and improved the caregivers' understanding of the psychological and behavioral aspects of HD<sup>2,16,24</sup>. As a result, the conflicts between the caregivers and the people with HD decreased. In addition, studies have shown that the QoL of HD caregivers is affected by the time that a person acts as a caregiver—a duration of more than five years is associated with a lower QoL<sup>9,24</sup>. On the other hand, caregivers who possess a greater knowledge of the disease had better QoL<sup>2,24</sup>. This finding demonstrates the benefits of education and guidance in the context of rare genetic diseases<sup>24,26,27</sup>.

Another factor that may have contributed to the improvement was the increase in the ability to seek conflict resolution reported by the participants. The intervention also presented methods to reduce stress in the face of a problem (such as breathing and mindfulness techniques or asking to talk later with a person about the conflict); the caregivers implemented some of these methods in their daily lives. Moreover, mindfulness practices are intended to lead participants into a state of focused attention via meditation aimed at directing their attention to the present moment, and have been used as a training strategy for intentional self-regulation<sup>20</sup>. The participants' self-reports about mindfulness practices were very positive. The literature points to several benefits of mindfulness practice: increased emotional regulation, lower reactivity, decreased

stress, and possible improvements in the therapeutic relationship<sup>20,21</sup>.

Third, our interventions, which are based on NVC<sup>15</sup>, also expanded the caregivers' views of their own feelings and needs. Previously, such feelings and needs were often neglected in favor of the needs of the person with HD. With these consultations, patients were able to expand their behavioral repertoire while remaining focused on emotions and communication. That ability conferred positive effects on their interpersonal relationships. Finally, it is important to emphasize that psychological care offers tools for participants to deal with the issues in their daily lives (e.g., work routine), exercising emotional self-regulation, and boosting their communication skills. All of these tools can help reduce their burden experience.

### Limitations

This study has limitations. Our sample size is small and does not allow statistical power to generalize the results obtained for men caregivers of people with HD. However, the present exploratory data can be used to support future large studies. We had an absence of control. We cannot make any statement about the number of hours that each caregiver spent in caring, the severity of disability and dependence of the HD people. In addition, it is difficult to analyze the psychological factors individually. One of the participants is the daughter of a person with HD, which probably has a significant impact on overburden. It is also fundamental that the sample

be expanded and carried out in a more representative way to allow generalization of the results to people in all stages of HD including early stages.

### Future directions

In conclusion, we have shown that an online neuropsychological intervention can reduce the burden of caregivers watching over HD people. The QoL and mental health of such caregivers are significantly affected by the burden of the caring routine and aspects inherent to HD. It is crucial that larger studies be carried out that investigate the burden experienced by caregivers of both sexes. We recommend obtaining outcome measures at baseline and post-intervention and incorporating a control group. We also advocate for and to evaluate the effectiveness of interventions performed with the caregivers overseeing patients in different stages of HD.

### AUTHORS' CONTRIBUTIONS

THS: conceptualization, formal analysis, funding acquisition, writing – original draft, writing – review & editing. FNP: conceptualization, formal analysis, funding acquisition, writing – original draft, writing – review & editing. TNM: conceptualization, formal analysis, funding acquisition, writing – original draft, writing – review & editing. LOL: funding acquisition, writing – original draft, writing – review & editing. TTCC: conceptualization, funding acquisition, writing – original draft, writing – review & editing.

### REFERENCES

1. McColgan P, Tabrizi SJ. Huntington's disease: a clinical review. *Eur J Neurol*. 2018;25(1):24-34. <https://doi.org/10.1111/ene.13413>
2. Banaszkiwicz K, Sitek EJ, Rudzińska M, Sołtan W, Sławek J, Szcudlik A. Huntington's disease from the patient, caregiver and physician's perspectives: three sides of the same coin? *J Neural Transm (Vienna)*. 2012;119(11):1361-5. <https://doi.org/10.1007/s00702-012-0787-x>
3. Capato TTC, Cury RG, Tornai J, Fonoff ET, Guimarães R, Jacobsen MT, et al. Use of objective outcomes measures to verify the effects of ICF-based gait treatment in huntington's disease patient on globus pallidus deep brain stimulation: a case report. *Front Rehabil Sci*. 2022;3:849333. <https://doi.org/10.3389/fresc.2022.849333>
4. Associação Brasil Huntington. Perguntas frequentes [Internet]. 2016 [cited on Nov 2, 2022]. Available from: <https://abh.org.br/perguntas-frequentes/>
5. Hergert DC, Cimino CR. Predictors of caregiver burden in Huntington's disease. *Arch Clin Neuropsychol*. 2021;36(8):1426-37. <https://doi.org/10.1093/arclin/acab009>
6. Capato TTC, Piemonte ME. Fisioterapia neurofuncional em indivíduos com doença de Huntington. In: Faria C, Leite H, eds. PROFISIO programa de atualização em fisioterapia neurofuncional. Porto Alegre: Artmed; 2022. p. 35-53.
7. Roscoe LA, Corsentino E, Watkins S, McCall M, Sanchez-Ramos J. Well-being of family caregivers of persons with late-stage Huntington's disease: lessons in stress and coping. *Health Commun*. 2009;24(3):239-48. <https://doi.org/10.1080/10410230902804133>
8. Rodríguez-Agudelo Y, Chávez-Oliveros M, Ochoa-Morales A, Martínez-Ruano L, Camacho-Molina A, Paz-Rodríguez F. Psychological discomfort in carriers and non-carriers of the Huntington disease mutation and its relationship with disease burden. *Neurologia (Engl Ed)*. 2022;S2173-5808(22)-00092-X. <https://doi.org/10.1016/j.nrleng.2022.06.005>
9. Figueiredo CG, Chaves CMCB, Duarte JC. Sobrecarga física, emocional e social dos cuidadores informais, familiares [dissertação]. Viseu: Instituto Politécnico de Viseu, Escola Superior de Saúde de Viseu; 2012.
10. Quagliato EMAB, Viana M. Orientações aos cuidadores. In: Quagliato EMAB, Marques MGN, eds. Doença de Huntington: guia para famílias e profissionais de saúde. Atibaia: Associação Brasil Huntington; 2009. p. 173-81.
11. Huang SS. Depression among caregivers of patients with dementia: associative factors and management approaches. *World J Psychiatry*. 2022;12(1):59-76. <https://doi.org/10.5498/wjp.v12.i1.59>
12. Au A, Gallagher-Thompson D, Wong MK, Leung J, Chan WC, Chan CC, et al. Behavioral activation for dementia caregivers: scheduling pleasant events and enhancing communications. *Clin Interv Aging*. 2015;10:611-9. <https://doi.org/10.2147/CIA.S72348>
13. Au A, Yip HM, Lai S, Ngai S, Cheng ST, Losada A, et al. Telephone-based behavioral activation intervention for dementia family caregivers: outcomes and mediation effect of a randomized controlled trial. *Patient Educ Couns*. 2019;102(11):2049-59. <https://doi.org/10.1016/j.pec.2019.06.009>
14. Castro LM, Souza DN. Programa de intervenção psicossocial aos cuidadores informais familiares: o cuidar e o autocuidado. *Revista Interações*. 2016;12(42):150-62. <https://doi.org/10.25755/int.11819>
15. Rosenberg MB. Comunicação não-violenta: técnicas para aprimorar relacionamentos pessoais e profissionais. 4a ed. São Paulo: Ágora; 2006.

16. Johnson AC, Paulsen JS. Understanding behavior in Huntington's disease: a guide for professionals. New York: Huntington's Disease Society of America; 2014.
17. Matos MA. Análise funcional do comportamento. *Estud Psicol (Campinas)*. 1999;16(3):8-18. <https://doi.org/10.1590/S0103-166X1999000300002>
18. Alves NNF, Isidro-Marinho G. Relação terapêutica sob a perspectiva analítico-comportamental. In: De-Farias AKCR, ed. *Análise comportamental clínica: aspectos teóricos e estudos de caso*. Porto Alegre: Artmed; 2010. p. 66-94.
19. Linehan MM. *Treinamento de habilidades em DBT: manual de terapia comportamental dialética para o terapeuta*. 2a ed. Porto Alegre: Artmed; 2017.
20. Tang YY, Hölzel BK, Posner MI. The neuroscience of mindfulness meditation. *Nat Rev Neurosci*. 2015;16(4):213-25. <https://doi.org/10.1038/nrn3916>
21. Davis DM, Hayes JA. What are the benefits of mindfulness? A practice review of psychotherapy-related research. *Psychotherapy (Chic)*. 2011;48(2):198-208. <https://doi.org/10.1037/a0022062>
22. Youssov K, Audureau E, Vandendriessche H, Morgado G, Layese R, Goizet C, et al. The burden of Huntington's disease: a prospective longitudinal study of patient/caregiver pairs. *Parkinsonism Relat Disord*. 2022;103:77-84. <https://doi.org/10.1016/j.parkreldis.2022.08.023>
23. Vitorino LM, Yoshinari Júnior GH, Gonzaga G, Dias IF, Pereira JPL, Ribeiro IMG, et al. Factors associated with mental health and quality of life during the COVID-19 pandemic in Brazil. *BJPsych Open*. 2021;7(3):e103. <https://doi.org/10.1192/bjo.2021.62>
24. Dinis A, Santos H, Martins R. Qualidade de vida dos cuidadores informais de doentes de Huntington. *Millenium*. 2016;2(ed espec 1):203-10.
25. Day AM, Alston PP. Stress in primary caretakers of chronic physically disabled children and adults. *Rehabilitation Psychology*. 1988;33(2):113-9. <https://psycnet.apa.org/doi/10.1037/h0091683>
26. Haddad MS, Capato TTC, Azambuja MJ. Huntington's disease. In: Chien H, Barsottini O, eds. *Movement disorders rehabilitation*. Cham: Springer; 2017. p. 115-28. [https://doi.org/10.1007/978-3-319-46062-8\\_8](https://doi.org/10.1007/978-3-319-46062-8_8)
27. Capato T, Haddad M, Barbosa E, Piemonte ME. Evidence-based Brazilian Physicaltherapy Guideline for Huntington's Disease [abstract 494] [Internet]. *Mov Disord*. 2017;32(2) [cited on Nov 02, 2022]. Available from: <https://www.mdsabstracts.org/abstract/evidence-based-brazilian-physicaltherapy-guideline-for-huntingtons-disease/>