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Case Report

Applying Dignity Therapy to a person with Amyotrophic Lateral Sclerosis: a case study

Aplicação da Terapia da Dignidade em uma pessoa com Esclerose Lateral Amiotrófica: um estudo de caso

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ABSTRACT

Introduction: To understand the effects of Dignity Therapy on the physical, existential, and psychosocial symptoms of a person with Amyotrophic Lateral Sclerosis.

Method: This is a single case study exploratory, and descriptive employing a mixed method approach. In it, Dignity Therapy was applied to an individual diagnosed with Amyotrophic Lateral Sclerosis, and its effectiveness was assessed using the following scales: the Patient Dignity Inventory, the Hospital Anxiety and Depression Scale, the Spiritual Well-being Scale, and the Edmonton Symptom Assessment Scale.

Results: The application of Dignity Therapy was assertive for the intended objectives, considering the reported improvement in the participant's existential well-being, made possible by the evocation of significant memories that culminated in the creation of a legacy document for future generations. These improvements were also corroborated by lower scores on the assessment scales.

Conclusion: The results of this case point to the positive effects of Dignity Therapy on physical, existential, and psychosocial symptoms, suggesting the feasibility of this intervention as an integral part of palliative care. Such an approach can help improve quality of life and give new meaning to the suffering inherent in the disease.

Keywords: Palliative Care; Dignity; Amyotrophic Lateral Sclerosis; Psychotherapy; Emotional Distress.

RESUMO

Introdução: Compreender os efeitos da Terapia da Dignidade sobre os sintomas físicos, existenciais e psicossociais de uma pessoa com Esclerose Lateral Amiotrófica.

Método: Trata-se de um estudo de caso único, exploratório e descritivo, empregando uma abordagem mista. Nele, a Terapia da Dignidade foi aplicada a um indivíduo diagnosticado com Esclerose Lateral Amiotrófica, e sua eficácia foi avaliada por meio das seguintes escalas: Inventário da Dignidade do Paciente, Escala Hospitalar de Ansiedade e Depressão, Escala de Bem-Estar Espiritual e Escala de Sintomas de Edmonton.

Resultados: A aplicação da Terapia da Dignidade foi assertiva para os objetivos pretendidos, considerando o relato de melhora relacionada ao bem-estar existencial do participante, possibilitada pela evocação de lembranças significativas que culminaram na criação de um documento legado destinado às gerações futuras. Estas melhorias também foram corroboradas pela diminuição dos escores nas escalas de avaliação.

Conclusão: Os resultados deste caso apontam para a produção de efeitos positivos da Terapia da Dignidade nos sintomas físicos, existenciais e psicossociais, sugerindo a viabilidade desta intervenção como parte integrante dos cuidados paliativos. Tal abordagem pode contribuir para a melhoria na qualidade de vida e ressignificação do sofrimento inerente à doença.

Palavras-chave: Cuidados Paliativos; Dignidade; Esclerose Lateral Amiotrófica; Psicoterapia; Sofrimento Emocional.

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INTRODUCTION

The subject of human suffering is directly linked to Palliative Care (PC), especially within the therapeutic process developed between professionals and patients. PC is a therapeutic measure that seeks to prevent and alleviate the physical, emotional, and social suffering of individuals and their families in the face of life-limiting illnesses. Considering their importance, regardless of the stage of the disease, PC should be part of professional health practice, both for diseases with no prospect of a cure and for chronic degenerative diseases.[1]

Researching the suffering of patients undergoing PC, Canadian psychiatrist and palliativist Harvey Max Chochinov developed the Dignity Model. Based on empirical research involving cancer patients undergoing PC, he identified internal and external factors that influenced the sense of dignity, divided into three main categories: Disease-Related Concerns, Dignity Conservation Repertoire and the Social Dignity Inventory.[2]

The Dignity Model inspires interventions designed to alleviate the multidimensional suffering of people undergoing PC. Among these interventions is Dignity Therapy (DT), which consists of a brief, individualized psychotherapy that allows reflection on important facts in the life of the person in the process of finitude, helping to improve existential and psychosocial anguish.[2]

During DT, it is recommended that patients share stories and themes that they want to be remembered for. The product of this intervention is called a legacy document, which can be passed on to subsequent generations by the person in the process of dying. In this way, DT seeks to preserve and promote interpersonal relationships, enabling a dignified end of life.[3]

By implementing actions that prioritize autonomy, self-care and valuing the human being, the professional from the PC team preserves the dignity of patients in the process of finitude, promoting quality of life[2], considered essential for people with chronic and degenerative diseases, such as Amyotrophic Lateral Sclerosis (ALS).

ALS is considered to be the most common degenerative disease among motor neuron pathologies, developing progressively and irreversibly. However, it has a low incidence in the population, with approximately 16 new cases per 100,000 people.[4] Its classic symptoms involve progressive weakness, muscle atrophy, fasciculations, muscle cramps, spasticity, dysarthria, dysphagia, dyspnea and emotional lability. Life expectancy after the onset of symptoms is usually between three and five years. These symptoms lead to total functional dependence, threatening the person's life.[4–6]

It is well known that, from the moment of diagnosis, people with diseases such as ALS experience irreparable loss. Studies indicate that these patients experience more negative emotions, such as hopelessness and helplessness, due to their limiting physical condition, compared to cancer patients.[7] This results in anticipatory grief, caused by the countless losses caused by the illness and the process of finitude.[8]

In light of this, studies published since the early 2000s have proven the benefits of DT for people undergoing PC. Going beyond the limits of standard care, DT provides comfort to patients and is well accepted and considered useful by family caregivers.[7] Given these aspects, the aim of this study is to understand the effects of DM on the physical, existential, and psychosocial symptoms of a person with ALS.

METHOD

This is a single case study, exploratory and descriptive, with a mixed approach, involving the intervention of DT in a person with ALS. The case study is characterized by an in-depth design, capable of preserving the unitary character of the phenomenon studied, without separating it from its context. To do this, multiple procedures are used to collect data, which are then contrasted with each other, providing an overview of the problem presented or identifying factors influencing its occurrence.[9]

The study was carried out at a neuromuscular outpatient clinic in the Brazilian state of Bahia, which provides free care to the population through partnerships with the Municipal Health Secretariat (*Secretaria Municipal da Saúde*, SMS) and the Brazil's Unified Health System (SUS). It is linked to a higher education institution and, as well as being a reference for the treatment of ALS, stands out for its commitment to quality of life and clinical research into health promotion. Data collection took place in March and April 2022.

The participant selected was being monitored at this clinic and showed signs of physical, existential and psychosocial suffering. Although his cognition was preserved, his speech was barely intelligible. He used writing and typing on electronic devices as a means of communication. For the purposes of the research, the pseudonym João was used when referring to him.

Dignity Therapy requires eligibility criteria and can be applied to anyone who is facing a life-limiting or life-threatening illness, as long as life expectancy is greater than two weeks and there is an interest in participating in the therapy. However, some conditions, such as cognitive impairment, can hinder or prevent the application of DT, as they compromise the participant's ability to reflect on their life.[2]

The application of Dignity Therapy (DT) follows three stages. In the first, the therapist invites the participant to the first meeting, explains how DT works, presents the twelve guiding questions and presents them with the Informed Consent Form (ICF) to sign. The participant can clarify any doubts and, if they accept, the next session is scheduled. The second stage is the application of the therapy, where the participant can choose to be accompanied by a family member, caregiver, friend, professional or be alone, just with the therapist. The session lasts from 30 min to 1 h and can be extended or divided according to the participant's needs. During the session, the therapist records the participant's narrative about their life. In the third and final stage, the therapist transcribes and organizes the narrative into a book format, keeping the essence of the participant's history. Additional sessions are then scheduled to review and adjust the document before final delivery.[2]

Due to the COVID-19 pandemic at the time, the research was conducted remotely to avoid contagion, using a digital recorder and an online meeting platform. The first meeting was aimed at the initial approach, where João (a fictitious name) was invited to take part in the research and signed the Free and Informed Consent Form after receiving the necessary explanations.

Two meetings were then dedicated to carrying out the DT. There were also three different times when the four DT assessment scales were applied: before DT (time zero), seven days after DT (time one) and 28 days after the intervention (time two). The scales used were the Dignity Inventory (PDI-Br), the Hospital Anxiety and Depression Scale (HADS), the Spiritual Well-Being Scale (FACIT-Sp) and the Edmonton Symptom Assessment Scale (ESAS). Finally, a face-to-face meeting was held to deliver the legacy document, the final product of the DT application.

As for the four scales used to assess Dignity Therapy (DT), the PDI-Br is derived from Chochinov's Dignity Model and aims to assess suffering related to the dignity of people in the process of dying. This instrument has 25 items, with scores ranging from zero to five. A score of three or more indicates greater suffering, with the overall sum of the inventory ranging from 25 to 125 points.[10]

The HADS scale, on the other hand, identifies symptoms of anxiety and depression in non-psychiatric patients admitted to hospital units. It consists of 14 items, divided into anxiety and depression. Values higher than eight points indicate probable cases of anxiety or depression.[11]

The FACIT-Sp measures spiritual well-being and a sense of purpose in life. Made up of 12 items, it assesses aspects such as meaning/peace and faith, with scores ranging from zero (not at all) to four (very much). The higher the score, the better the quality of life and well-being.[12]

Finally, the ESAS is used to assess symptoms such as pain, fatigue, nausea, sleep, anxiety and dyspnea. The intensity of symptoms is scored from zero to ten, where higher values indicate a worsening of symptoms.[13]

The data was analyzed from two perspectives. In the first, of a qualitative nature, content analysis was used to understand the positive or negative effects of Dignity Therapy (DT) on the participant, focusing on physical, psychosocial, and existential suffering, based on the answers obtained through a semi-structured interview.[14] This study complied with the recommended ethical and scientific premises, complying with the Guidelines and Standards for Research Involving Human Beings of Resolution 466/2012 of the Brazil's National Health Council, and observing the ethical principles of research in the Humanities and Social Sciences, in accordance with Standard 510/16.The research was sent to the Research Ethics Committee, and collection began after its approval (Decision number 4 952 826, approved on September 3rd, 2021), following the guidelines for research procedures in the virtual environment, according to Circular nº 2/2021/CONEP/SECNS/MS (Brazil's Ministry of Health).

RESULTS

The results were organized in the form of a table (Table 1), containing the variation in scores related to the four distress assessment scales. The material shows a reduction in the scores of the scales responsible for measuring psychosocial and physical distress, showing a reduction in suffering in these spheres. On the other hand, the FACIT-Sp scale showed an increase in scores, indicating an improvement in spiritual well-being and meaning of life. These results were corroborated by the data presented in Chart 1, which shows the aspects observed and narrated by the participant during therapy and application of the scales. In this chart, the suffering experienced by the participant was stratified based on the main categories of the Dignity Model: concerns related to the illness, the repertoire for preserving dignity and the Social Dignity Inventory.

DISCUSSION

The current study illustrates the construction of a legacy of dignity, which showed an improvement in existential well-being, based on the retrieval of memories that were important to the participant, allowing his speech to be eternalized in a document that will be passed on to future generations. Some authors have pointed out that DT can be an effective, low-cost and individualized approach to PC.[7,15]

Table 1. Application of Dignity Therapy assessment tools. Salvador, BA, Brazil, 2022.

Scales	João		
	T1	T2	T3
Patient Dignity Inventory (PDI-Br) (minimum 25/maximum 125)	65	28	37
Hospital Anxiety and Depression Scale (HADS)			
Anxiety (minimum 0/ maximum 21)	4	4	3
Depression (minimum 0/ maximum 21)	5	5	6
Spiritual Well-being Scale (FACIT – Sp-12) (minimum 0/ maximum 48)	32	36	39
Edmonton Symptom Assessment Scale (ESAS – r) (minimum 0/ maximum 10)			
Pain	0	0	0
Fatigue (weakness)	3	0	0
Nausea	0	0	0
Sadness	3	0	3
Anxiety	3	0	0
Drowsiness	3	0	0
Appetite	5	0	0
Feeling of well-being	5	3	2
Dyspnea	0	0	0
Sleep	3	0	2

Notes: T – Baseline (2 days before DT); T2: 1st week follow up (7 days after intervention); T3: 4th week follow up (28 days after intervention).
Source: Data from the authors.

It is known that the population affected by ALS is mostly male, between 55 and 75 years old, more precisely, from the fifth decade of life onwards.[17] In this study, symptoms were identified at the age of 29 and the diagnosis was confirmed at 31. Seven years after diagnosis, a curve of functional decline is observed, with aphasia and partial dependence in activities of daily living representing major challenges. However, the preservation of cognitive capacity, a characteristic of the disease, still allows a certain amount of autonomy to be maintained.

In most cases, lucidity remains until the end of life. Although cognitive or behavioral changes may appear, it is important to note the restrictions on assessment, since patients' speech and writing are impaired.[5,16]

This "lucidity", which allows the exposure of wishes and desires, favors a direct understanding of the losses resulting from the path of illness. This confrontation with lived reality can be a potentiator for psychological suffering.[17] When trying to express that he had overcome the idea that his physical capacity was declining, the participant showed disbelief at the fact that the doctors who accompanied him were not open to the idea of a possible cure.

Through the PDI-Br scores, a discourse of improvement in psychological suffering was identified, when the subject claimed to feel "lighter and calmer" every day. However, improvement depends on the individual's desire to access information about what is essential to them and transform this contact into something more lasting.

However, becoming aware of an incurable and serious illness gives rise to distressing feelings and questions about the limits of one's resistance. The greater the uncertainty, the more intense the existential suffering. These feelings are not only the result of physical pain but are also intrinsically linked to the social context and the experiences lived before and during the diagnosis of ALS. Among the causes of this suffering are the pact of silence established between patient and family to avoid confronting the truth of the disease, denial of one's own condition and its prognosis, as well as feelings of guilt, fear of death, anxiety, depression and a sense of loss of meaning in life.[18]

Depression at the end of life is not always pathological but is the result of suffering in the face of impotence in achieving a cure. Anxiety is associated with uncertainties about the future and/or not understanding or accepting finitude.[19]

Despite the suffering experienced as a result of the disease, the participant gave a speech full of professional and family achievements, showing pride in affirming his lived trajectory. DT allows us to discover or remember who has gone and to believe that their life still has value, honoring their existence.[17]

The definition of being a sufferer of an incurable and progressive disease allows people to explore different ways

Chart 1. Qualitative and quantitative data collection. Salvador, BA, Brazil, 2022.

Getting to know Mr. João	**Concerns related to the disease:** Male, 36 years old, married with a marital separation in process, father of two children, evangelical. He previously worked as a first aider and emergency transport driver but is currently retired due to the functional limitations caused by ALS. Despite his physical mobility difficulties, he has good cognitive acuity. Symptoms of the disease began in 2015, and the diagnosis was confirmed in 2017. His speech is barely intelligible, and he resorts to handwriting or typing to communicate. During the assessments and interventions, she showed no apparent physical distress. However, her self-image received a high score on the PDI-Br, despite considering the changes in her appearance to be a “small problem”. Regarding psychological suffering, signs of sadness, devaluation, isolation and social distancing were observed in his speech, with attempts to hide his suffering. He expressed uncertainty about the future and questioned scientific knowledge about ALS, showing awareness of his condition but reluctance to accept the losses resulting from the progression of the disease. **Perspectives on preserving dignity:** The search for spiritual comfort is a significant part of his life, evidenced by expressions of religiosity and faith in God as a source of happiness. He shows a desire to re-establish family life with his ex-wife and children as a way of preserving his identity and continuity. The lack of family contact causes perceptible suffering, highlighting the conflict between acceptance, resilience and the desire for normality. Despite this ambiguity between desire and reality, he faces adversity with adaptations and does not see death as an immediate obstacle, declaring that he is not afraid of it. At all times, he strives to leave a record of his happy moments, hoping that his story will be remembered for generations to come. **Social dignity inventory:** There is little social support in the narrative. He imposes limits on his privacy, showing himself to be reserved and not allowing the therapist to reach his limbic memory. His social network is restricted to his mother, wife, children and older sister, with no mention of other family members. This restricted social support, coupled with the privacy limits imposed by the progression of the disease, leads the participant to feel like a burden to others, generating concerns about the future of his mother and children. Care is not considered a problem in the PDI-Br applications, but the participant highlights the resistance of the professional team to accepting a possible cure for the disease publicized on social media.
Time 0	The first application of the four scales (PDI-Br, HADS, FACIT-Sp and ESAS) took place two days after the participant agreed to take part in the research, during a video call via the Zoom platform. The scales were read out and explained by the researcher to the participant, who answered the questions asked. The entire application process took around 30 min. The participant showed no difficulty in understanding the questions.
Application of the DT intervention	It took place in two sessions, each lasting approximately 90 min. It was spoken by typing into a video call application. The report was edited, and the first version was presented in a recorded virtual session, using the Zoom platform, where feedback was given, and some changes and reorganizations of ideas were made at the participant’s request. Finally, the legacy document that was given to him was generated.
Interview	When asked what it was like to undergo therapy and how he felt, he responded positively, mentioning a feeling of lightness, tranquility and letting off steam. He also pointed out that he had noticed changes in the spiritual dimension post-DT. *The therapy was something different for me, but I really enjoyed the experience [...] I’ve felt lighter and calmer, because I’ve never shared these details with anyone [...] my spiritual life has improved day by day[...]*
Time 1	The second application of the DT assessment scales took place seven days after the therapy, also virtually. The whole process lasted around 30 min and was a peaceful and apparently enjoyable time for the participant.
Time 2	The third application of the scales showed no complications or anything that could be highlighted in relation to Moment 1.

Source: Data from the authors.

of dealing with reality. While experiencing suffering, a wide range of feelings and emotions are triggered, including the feeling of loss of autonomy and free will. Mr. João revisited stories and memories that touched him deeply, rescuing the essence of the person who experienced them.

When considering the perspective of the continuity of the Self, the participant identified the feeling of no longer being who he was, of not feeling useful and valued, and of not being able to play important roles as crucial points of anguish. However, throughout the construction of the legacy document, these were re-signified and minimized to minor problems. This may have evoked the memory of a history full of struggles and achievements, serving as a driving force for them. Even with physical limitations and a fragile support network, the participant points to a preservation of autonomy. However, it is essential to question whether this belief is based on a perspective of curative treatment promoted by media reports.

The hope that something good will happen is also glimpsed in traits of resilience, which consists of having the courage to face the unknown, possessing a kind of spiritual and psychological support, backed by beliefs and the perception of a purpose.[3] These elements are capable of mitigating any outcome caused by the disease. For some people, the certainty of finitude can become the meaning of life, while for others, any extra minute of life is synonymous with hope.

Faith in God allows Mr. João to hold out hope of participating in experimental treatments that could stop or even cure ALS. Moreover, this belief comforts him in times of suffering, giving him inner peace and eliminating his fear of death. During Dignity Therapy, Mr. João points out that his faith has increased since his diagnosis, realizing that faith in God is essential to finding happiness.

In addition to the internal factors described above, external factors also influence existential well-being, leading to a reduced sense of dignity. These factors are described in the third category of the Dignity Model, as the Social Dignity Inventory.[2]

The loss of privacy is subtly observed by the participant, who mentions the need to be constantly cared for by his mother as his physical limitations progress. Although it was categorized as "a big problem" in the PDI-Br and showed a slight improvement after Dignity Therapy, this aspect remains significant for him.

This is the first challenge imposed by the disease, and as it progresses, simple everyday tasks such as bathing, dressing and feeding become part of the caregivers' routine. This leads to a minimal reduction in the person's privacy at the end of life. Increased dependency also leads to a breakdown in roles or an altered sense of self, which can result in feeling like a burden to others.[2]

For Mr. João, control over his own life was lost with the evolution of ALS. In this way, he expresses a sense of guilt, feeling responsible for the physical and emotional strain on his elderly mother when caring for him. This feeling becomes stronger as the disease progresses, making it painful for the person at the end of life to bear the full burden of disabilities and needs directed at the caregiver/family member.[2]

This complaint was confirmed in the application of the PDI-Br, and reduced considerably after therapy, going from "a big problem" to a "small problem". The participant said that exposing "particularities" during the DT made him feel "lighter and calmer".

An external factor considered important and essential for a sense of dignity is social support. A person at the end of life and their social support are seen as a unit for the PC model. This support is of great importance, not only at an operational level, but also as psychological support, and is also responsible for existential well-being.[2,8] However, this factor is weakened in the participant's discourse, since he reports the loss of his main caregiver, his wife, with this figure replaced by his elderly mother who has difficulty accepting his illness. Although he has a relatively large family, he reports that there is no good family interaction. In addition, being retired and unable to increase his income makes it difficult to hire care services.

As for the Care Content approach, the participant notes a lack of enthusiasm on the part of the doctors when he mentions possible treatments publicized in the media as potential cures for the disease. The hope of having his autonomy back, of perceiving himself as the "old me", possibly leads him to this judgment. Other behaviors are not mentioned by the participant, with no changes after the DT in the PDI-Br question related to "not feeling support from the health professionals who look after him", which at all times had the answer "it's not a problem".

Finally, during Dignity Therapy, Mr. João expresses concerns about future consequences, mentioning his worry about the fate of his children and concerns about his personality and character. He also shares his desire to get back together with his family, including his ex-wife and children. Although he claims not to be citedafraid of death, he clings to his faith in God to determine his fate, but stresses that he will not give up looking for alternative treatments in the hope of finding a cure.

CONCLUSION

The findings of this study reveal the beneficial implications of applying DT on the physical, existential, and psychosocial symptoms of people with ALS. Before therapy, the participant exhibited signs of sadness, suffering and social isolation, along with a difficulty in accepting and understanding the natural course of his illness. These symptoms were aggravated by the lack of family interaction, which further weakened his social relationships.

On the other hand, he employed strategies to find spiritual comfort, resilience and maintain his dignity, highlighted by the expression of his religiosity. In addition, he expressed a desire to document his life story to be remembered by future generations.

After undergoing Dignity Therapy, the participant showed significant changes in his spiritual dimension, existential well-being and psychological distress, as evidenced by the scores on the assessment scales used in the study. Moreover, the preparation of the legacy document, intended for future generations, allowed the recovery of important memories and the preservation of his narrative, essential aspects for protecting his dignity.

The limitations of this study were the fact that the participants communicated only in writing, restricting their narrative and often requiring encouragement from the researcher to better develop each topic addressed.

From this study, it becomes clear that Dignity Therapy is a viable intervention for people in palliative care who face challenges to their dignity, experiencing various forms of suffering, as discussed above. As such, Dignity Therapy can be implemented in a variety of settings, both face-to-face and remotely through online meeting platforms. It is essential that the palliative care team receives adequate training to guarantee the participant's privacy and welcome.

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