

CONSIDERATIONS OF THE CAREGIVERS' PERCEPTION REGARDING THE CARE OF PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS

CONSIDERAÇÕES DA PERCEPÇÃO DOS CUIDADORES DIANTE DO CUIDADO COM PACIENTES COM ESCLEROSE LATERAL AMIOTRÓFICA

CONSIDERACIONES DE PERCEPCIÓN PROFESIONAL ANTES DE CUIDAR A PACIENTES CON ESCLEROSIS AMIOTRÓFICA LATERAL

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ABSTRACT

Objective: To analyze the caregivers' considerations regarding patients diagnosed with amyotrophic lateral sclerosis to obtain a better understanding of their mental health. **Method:** This is an integrative review of the literature of a narrative character, carried out through the VHL Brazil, BVSalud, Lilacs, Pepsic databases and ABRELA, between April and May 2020. Articles in Portuguese were included, including caregivers, mental health related to patients diagnosed with amyotrophic lateral sclerosis. **Results:** From the first symptoms of amyotrophic lateral sclerosis to the moment of death, the patient and his caregiver undergo significant emotional and social disturbances, which contribute negatively to the quality of life of both. Caregivers, mostly women and relatives, had levels of perceived overload and neglected attention to themselves. **Conclusion:** It is concluded that caregivers need greater tools that enable the maintenance of their psychological aspects, generating greater quality of life.

Descriptors: Terminally ill; Palliative care; Mental health; Caregivers.

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RESUMO

Objetivo: Analisar as considerações dos cuidadores de pacientes diagnosticados com esclerose lateral amiotrófica para obtenção de melhor compreensão quanto sua saúde mental.

Método: Trata-se de uma revisão integrativa da literatura de caráter narrativo, realizada através das bases BVS Brasil, BVSalud, Lilacs, Pepsic e site da ABRELA, entre abril e maio de 2020. Foram incluídos artigos no idioma português onde considera-se cuidadores, saúde mental relacionados a pacientes diagnosticados com esclerose lateral amiotrófica. **Resultados:** Desde os primeiros sintomas de esclerose lateral amiotrófica até o momento da morte, o paciente e seu cuidador, passam por perturbações emocionais e sociais significativas, das quais contribuem negativamente na qualidade de vida de ambos. Os cuidadores, em sua maioria mulheres e parentes, apresentaram níveis de sobrecarga percebida e atenção negligenciada a si mesmos. **Conclusão:** Conclui-se que os cuidadores necessitam de maiores ferramentas que possibilitem a manutenção de seus aspectos psicológicos, gerando maior qualidade de vida.

Descritores: Doente terminal; Cuidados paliativos; Saúde mental; Cuidadores.

RESUMEN

Objetivo: Analizar las consideraciones de los cuidadores de pacientes diagnosticados de esclerosis lateral amiotrófica para conocer mejor su salud mental. **Método:** Se trata de una revisión integradora de la literatura de carácter narrativo, realizada a través de las bases de datos BVS Brasil, BVSalud, Lilacs, Pepsic y sitio web ABRELA, entre abril y mayo de 2020. Se incluyeron artículos en portugués, incluyendo cuidadores, salud mental relacionados con pacientes diagnosticados con esclerosis lateral amiotrófica. **Resultados:** Desde los primeros síntomas de la esclerosis lateral amiotrófica hasta el momento de la muerte, el paciente y su cuidador sufren importantes trastornos emocionales y sociales, que contribuyen negativamente a la calidad de vida de ambos. Los cuidadores, en su mayoría mujeres y familiares, tenían niveles de sobrecarga percibida y descuidaban la atención hacia ellos mismos. **Conclusión:** Se concluye que los cuidadores necesitan mayores herramientas que permitan el mantenimiento de sus aspectos psicológicos, generando mayor calidad de vida.

Descriptor: Enfermo terminal; Cuidados paliativos; Salud mental; Cuidadores.

INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease that affects motor neurons, causing a gradual and progressive loss of motor neurons, paralyzing skeletal muscles and respiratory muscles, compromising motor skills, speech and swallowing. Its high lethality is associated with repercussions on respiratory capacity. Life expectancy after the appearance of the first symptoms is low, the average survival is three to five years, in the

case with bulbar involvement, survival is lower, from six months to three years.^{1,2}

Disease progression is considerably variable between patients. The average age of onset of symptoms is 57 years, the prevalence of its involvement is found in white individuals, proportionally, males are the most affected, with 2 male cases for 1 female. The clinical pictures of diseases that affect the motor neurons are: Progressive muscular atrophy; Primary lateral sclerosis; Progressive bulbar palsy; and ALS (the most common among the conditions). The disease

is rare and still has no cure prognosis, it has a complex diagnosis and rapid progression. Its main symptoms are weakness or muscle cramps in the limbs, spontaneous muscle contractions, stiff limbs, impaired speech and difficulty swallowing.¹

In cases of ALS, there is no compromise in the superior cortical functions, that is, the mental capacity is preserved throughout the process of bodily deterioration, intelligence, judgment, memory and sense organs do not undergo changes. The individual consciously accompanies all the rapid transformation of his own body, the loss of functionality and the growing dependence on the other, evidently such a situation generates intense psychic and mental suffering in these subjects.^{1,3} The entire family close to the patient suffers with the progression and worsening of the condition; however, usually only one person assumes the daily care for the subject, being responsible for physical, emotional, and in some cases financial assistance. Then, the quality of life of this primary caregiver is discussed, addressing the caregiver syndrome, characterized by a mental state that impacts all areas of this individual's life, with physiological, social, economic and psychological repercussions, which can result in dissatisfaction and frustration. This condition may render you unable to continue providing patient care.⁴ It is believed that

what is advised is that care for the caregiver should start when the new family configuration identifies who will acquire this role.⁵ The objective is to analyze the considerations of caregivers of patients diagnosed with ALS, in order to obtain a better understanding of their mental health.

METHOD

The model of integrative literature review of a narrative nature is used, based on the systematic survey of bibliographic sources with the intention of including experimental and non-experimental studies, through a theoretical and contextual, analytical and methodological view of the research results based on in the search for evidence that provides a better understanding of the observed phenomenon to contribute, through current and deeper information, to the academic community.²⁵

Inclusion criteria for the selected studies were those published in Portuguese, related to caregiver topics, mental health related to patients diagnosed with amyotrophic lateral sclerosis, used as descriptors in the databases BVS Brasil, BVSalud, Lilacs, Pepsic, the website of ABRELA and Qualis Periodicals on the Sucupira Platform, between April and May 2020.

RESULT

From the first symptoms of ALS to the moment of death, the patient and his caregiver experience significant emotional and social disturbances, which negatively contribute to the quality of life of both. Defense mechanisms are used as a means of preserving mental, social and emotional integrity, allowing contact with the anguish and suffering that permeate such a disease. The multidisciplinary team that provides support at different times to the patient and caregivers also suffers from emotional exhaustion.⁵ The family and the caregiver of individuals with ALS, have a leading role in the treatment and adaptation to the new personal and social contingencies, which they are inserted from the first symptoms. Adaptation to the new psychosocial dynamics and the growing level of dependence will be directly influenced by the functionality of this social circle of assistance. Simultaneously, the caregiver ends up developing significant levels of overload, with a decrease in their leisure time, social relationships, intimacy, free time and emotional balance.⁶

The sociodemographic characteristics of caregivers coincide in the national and international field.⁷ Authors agree about some of the predominant characteristics in the group of caregivers, most of whom are women and are related to the patient.^{2,4,7-11} Three categories of tasks are performed by

the main caregiver: First, support in activities of daily living, including housework and commuting; Second, support in the practice of physical activities and in daily self-care, including personal hygiene, possible physical exercises, medication administration and food; And the third, emotional assistance, through companionship, demonstration of empathy towards emotions and conversation about different subjects.¹² However, the third scope, which directly influences the quality of life of both agents, is often neglected, in view of the greater energy that primary and secondary level activities require from the caregiver.⁴

Due to the multiple tasks performed in the care of an individual with ALS, it exhibits a complex quality, in view of the diversity of issues that the neurodegenerative condition presents and the objective and subjective care factors.^{8,9} For this reason, caregivers had a moderate burden, but there were differences in subjective perceptions among caregivers. Among them, those who lived in the same house as the patient, and therefore were more exposed to the effect of the degenerative process, had higher levels of tension.⁸

Often, the main caregiver is faced with such demands without adequate preparation and guidance, consequently, negative physical and psychological impacts may

occur on the caregiver and the patient.^{3,4,7,11} Contact with mortality, change in routine and time spent caring for the patient are variables with a direct impact on the individual's health and quality of life.⁷ It is important to promote and reflect on the considerations of caregivers who work directly with patients with ALS, thus allowing investigations that fully understand their perceptions. Effective scientific concern with caregivers of chronically ill patients began in the 1980s, due to changes in developed countries and in the sociodemographic and economic profiles of the population, resulting in an increase in the number of patients who needed monitoring and daily care in the home environment. Only recently did Brazil place the family caregiver as an object of investigation.¹² Although these individuals are a primordial resource in daily care, with assistance in the physical sphere, psychosocial and affective support, the greatest attention is paid to the patient's organic spheres.⁴

Due to the characteristics and prognosis of ALS, the patient and his/her caregiver can use immature defense mechanisms and develop symptoms of depression, anxiety, anger and denial. The attention of a multidisciplinary team is necessary throughout the treatment, helping the patient with palliative care, in addition to psychosocial support, assistance and guidance to family members.³ By listening

and understanding their anxieties, health professionals seek to involve the caregiver and family members in the patient's treatment, playing the role of an empathetic mediator of the weaknesses and needs among the agents, in addition, they often have the role of a guide in the search for resolutions linked to such situations.⁶ As ALS presents a degenerative and progressive course, its treatment is limited to therapies with the use of neuroprotective drugs, such care aims to enable measures that provide a better quality of life and make the progressive course of the disease as slow as possible.¹

A study specifies that in addition to depression and anxiety, individuals with ALS may experience feelings of despair, idealizations and suicidal attempts. With regard to caregivers, signs of exhaustion, stress and ambiguous feelings towards the person being cared for are common, generating guilt, in addition to depression.⁴ Accordingly, the quality of life of patients with ALS and their caregivers has a bilateral influence, that is, reciprocally, stability in the physical and psychological health of the caregiver can improve, or at least maintain, the good quality of life of individuals with ALS. Commonly, there is a negative impact on the caregiver's quality of life related to the longer time spent on care, and this point is elucidated when considering the gradual worsening of symptoms and the increase in

the patient's dependence.¹² The authors advise care and specific interventions linked to the dynamics of the relationship between patient and caregiver.

The lack and negligence of health care, social and interpersonal support aimed at caregivers are factors that negatively influence the quality of life of patients with ALS.^{12,13} Regarding caregivers, a study shows that those who care for individuals with high physical impairment and greater dependence, report a decrease in self-care, social interaction, residential changes and removal from formal jobs in order to meet the patient's demand.¹⁴

In the case of primary caregivers of individuals with ALS, a study addresses that the daily average dedicated to care exceeds 10 hours⁹, which contributes to the point of another study, when reporting the notoriety of the perceived burden related to the longer time spent in care.¹² This burden perceived by caregivers ranged from moderate to severe, in addition, impairments in the quality of mental health of these individuals were pointed out, specifically in the dimensions of vitality. In addition to the impacts on mental health, physical health was also influenced, the level of these changes was related to the level of perceived overload. The results also showed a relationship between the degree of functionality of the patient with the overload and health status of the caregiver.⁹

DISCUSSION

The predominance of the profile of caregivers has an average of 50 years, low education, married women and domestic workers. Commonly, caregivers show indicators of moderate burden.⁷ In a survey carried out with caregivers of patients with ALS, in addition to the prevalence of female gender and kinship, mentioned above, they reported that caregivers are mostly aged between 35 and 55 years, of which 66.6% performed caregiver activities for over a year.⁴

Another study agrees by pointing out that the primary caregiver's health can often be secondary in the name of the care needed by the patient, especially in cases where all responsibility is deferred to that single person.¹¹ The emotional support that the family directs to this main caregiver can be precarious, the overload claimed by these individuals was related to the lack of affective and objective support. Family caregivers presented loss, or restriction, of social support networks, arising from the impossibility of dividing time between frequent interpersonal interaction and the demand for necessary care.¹¹

When ALS affects the matriarch, all family dynamics are more incisively compromised, because usually the woman is responsible for the internal organization of this group. The woman is associated with

the social role of caregiver, when this function cannot be performed and she becomes the object of care, the individualistic structure of this particular family reconfigures itself in a way that meets the new needs, Through the solidarity mobilization of family members and their surroundings, with the role of vacant matriarch, usually another woman in the family occupies this position. Thus, the sociodemographic characteristic is maintained, one of the daughters or another parent becomes the primary caregiver of the patient, although the sociodemographic characteristic presented by these individuals is of married people, exceptionally the spouse will take the place of primary caregiver.³ A study addresses that the only caregiver, a male spouse analyzed, presented the level of extreme overload, considering the double responsibility required as a caregiver and as a material provider of the family.⁸

The physical and mental health of caregivers of patients with ALS is lower when compared to the normative level of the general population. The high demand for care experienced by caregivers makes daily demands a lot on the physical and psychological resources of these individuals. Elderly people often assume this high load of responsibility, considering the predominance of kinship ties, caregivers feel the task of caring for these individuals.¹⁵

With the progression of the disease and the gradual increase in dependency, daily coexistence can strengthen the affective ties between the agents, in this way, the negative determinants, such as tiredness and frustration, do not negatively influence the commitment and zeal deposited in the care of this subject.¹⁶

The philosophy of palliative care is centered on resources that guarantee humanized death, aiming at autonomy and respect for the feelings, preferences and desires of individuals regarding the control and processes of their own death. The main goal ceases to be treating, curing and controlling diseases, and becomes focused on relief, comfort and dignity in the dying process.¹⁷ Each person will have their own way of experiencing finitude, influenced by previous conceptions of death and dying, with social and cultural influences and previous contacts with this process.¹⁸

In this way, it is necessary to reflect on the conception of Death and Dying, because in the face of extreme situations and serious illnesses, such as ALS, these individuals are at all times involved with such contents, which are increasingly being avoided and socially denied. Death is a present and recurring theme throughout the history of the human species, over the centuries its conception has been modified in relation to different cultures and social organizations, man has sought and continues to seek,

through philosophical, religious, scientific and technologies the conscious distance from finitude.¹⁹ The ideology of perfection and health, is one of the bases that constitute all references in Western society today.¹⁷ The attempt to exclude the idea of death, through the desire to abolish it, in this way, man can sustain his illusion of continuity and permanence. It is as if to stay alive, man needs to stay away from the memory of his own mortality.²⁰

The theme of subjectivity in the face of death permeates hospital psychology, especially related to chronic and terminal conditions, such as ALS.²¹ Contact with patients without favorable prognosis and involvement with care aimed at reducing suffering leaves marks on this process, the way in which they will deal with such psychological demands will be influenced by the social dynamics between these agents in contact with individual perspectives and subjective.²²

Deepening and seeking to identify the psychological impacts at an emotional, affective level and on the quality of life of those who work directly in the integral care of patients with ALS and in the support of the patients' relatives, the result was an indication of the use of mature defense mechanisms and sensitivity to the patient's suffering. The constant contact with the intense suffering, the pain and the psychic suffering of the other, can cause psychic

disruption in which the defense mechanisms are imperative to reestablish the internal balance.²³

Some of the defenses against discomfort and negative feelings in the face of emotionally draining situations are distancing, denial, building a superficial relationship, depersonalization and institutionalization of actions through routine and protocols. These behaviors serve as psychological protection that pushes the individual towards the slightest direct contact with exhausting content. Faced with negative prognoses and the defensive behavior of the health team, the patient may find it difficult to establish trust with the professionals, thus reducing open communication, where the patient may have the perception of a lack of decision-making power and feel, himself, depersonalized of his individuality and subjectivity.²⁴

Considering the greater gap in the palliative framework that family caregivers have, it is understandable to find indicators of greater overload and strain in the mental and physical scope of this class. Family members who move around the patient with ALS are confronted by impotence when death approaches, generating in these individuals and in the patient himself, the process of anticipated mourning, and interpersonal conflicts between family members may occur, since the anticipatory mourning process can occur in disharmony

between these individuals, however, the progressive elaboration of this mourning generates humanitarian gain in all those involved in this process.³

CONCLUSION

Through the knowledge integrated in the present study, we can characterize the sociodemographic predominance of the primary caregivers of individuals with ALS, being essential for maintaining the quality of life of these patients, including in daily tasks. It is noteworthy that most are formed by chance with a prevalence of females, usually being relatives, with low education and their activities focused on domestic services, with a lack of technical preparation and previous guidance that can negatively impact the perception of such agents.

These women, in most cases daughters, wives or daughters-in-law, reconfigure the dynamics of their lives to provide the necessary care to these individuals. The parameters between the gender differences described here can be understood from the historical and social perspective of women in society, the roles assigned to the female gender have always been, in Western culture, linked to the care of the nuclear family, placed for centuries in the cyclical social position, while for men, the pressure of support and financial and material provider of this nuclear family was determined.

After being confronted by the ALS diagnosis of one of its members, the family undergoes a restructuring in its dynamics, especially the primary caregiver who streamlines a new external and internal system to meet this new demand. Attention is commonly neglected by caregivers about themselves. The caregiver's lack of care for himself and the uninterrupted concern for the individual being cared for, ends up generating more negative than positive consequences, since there is a bilateral relationship of psychological and physical health between both agents. Therefore, it is important to seek a configuration that manages to maintain the well-being of caregivers, stabilizing and improving the quality of these individuals, and, consequently, improving the quality of life of those who receive care.

The lack of support that the primary caregiver receives from the family is generally mentioned as one of the factors that can contribute to the overload. Since this is a disease with high mortality and apparent motor degeneration, this caregiver is often confronted with the reality of the other's mortality, and consequently, his own mortality. In view of the desired distancing from death, and the internalized idea of immortality in Western culture, this encounter with the suffering of the other can negatively influence the perception and mental health of this caregiver, in line with

data that point to levels of depression, anxiety and feelings negative effects such as frustration, hopelessness and impotence.

It is possible to measure the psychological impacts that the long contact with the pain of the other reflects on the individual, and the differentiation of the preparation that professionals focused on palliative care have, it is explicit the influence that the considerations and the internalized purpose on the health and psychological maintenance generates in different individuals. Less preparation, greater affective bond and uninterrupted contact with the unfavorable prognosis, make most of these family caregivers find themselves in greater psychological vulnerability.

As for the individual with ALS, the caregiver presents himself as a provider of a better quality of life, assisting him in the care of daily life and ideally providing social attention and psychosocial support linked to communication and interaction with the other. It is an agent of health and daily maintenance in all aspects related to the possible well-being of a patient who is under a psychic and physical load with great negative affect. Analogously when analyzing the role of the caregiver focused on the individual and according to his considerations, we find a health agent created by chance, which in the search to meet the demands and provide the other

with a quality of life, ends up sacrificing its own aspects, either for lack of time, support, or the great responsibility internalized, ends up overloaded through the objective questions of this care and its subjective questions, of which, in a normative way, will not be prepared to meet the new demands of the outside world.

This study aimed to analyze the perception of caregivers of individuals with ALS, but it is of fundamental importance to highlight its limitation, which was not intended to exhaust the subject, but the material used was an interest in discussing the themes of the theme, so it is opportune to highlight the need to develop more studies on the theme for further elucidation on the relationship between caregivers and patients with ALS.

In short, it is concluded that the caregivers of patients with ALS need more tools that allow the maintenance of their psychological aspects, generating a better quality of life for this class, and, nevertheless, the success in the search for greater stability will influence positively the individual who receives such care, thus having a broad positive impact.

REFERENCES

1. Associação Brasileira de Esclerose Lateral Amiotrófica. Esclerose lateral amiotrófica: atualização 2013 [Internet]. São Paulo: ABrELA; [201-] [citado em 20 maio 2020]. 46 p.

- Disponível em:
<http://www.abrela.org.br/default.php?p=texto.php&c=ela>
2. Anequini IP, Pallesi JB, Fernandes É, Fávero FM, Fontes SV, Quadros AAJ, et al. Avaliação das atividades da ABRELA: orientações oferecidas, expectativas atingidas? *Rev Neurociênc.* 2006; 14(4):191–7.
 3. Borges CF. Dependência e morte da “Mãe de família”: a solidariedade familiar e comunitária nos cuidados com a paciente de esclerose lateral amiotrófica. *Psicol Estud.* 2003; 8(esp.):21–9.
 4. Orsini M, Mello M, Lisieux D, Pássaro CP, Leite MAA, Baldez AC, et al. Qualidade de vida de cuidadores e pacientes com diagnóstico de esclerose lateral amiotrófica. *Rev Neurociênc.* 2012; 20(2):215–21.
 5. Abreu-filho AG, Oliveira ASB, Silva HCA. Aspectos psicológicos e sociais da Esclerose Lateral Amiotrófica: revisão. *Psicol Saúde Doenças.* 2019; 20(1):88-100.
 6. Rodrigues G, Winck JC, Silveira F, Almeida J. Avaliação sociológica de doentes com esclerose lateral amiotrófica. *Rev Port Pneumol.* 2002; 8(6):645-53.
 7. Amendola F, Oliveira MA de C, Alvarenga MRM. Qualidade de vida dos cuidadores de pacientes dependentes no programa de saúde da família. *Texto & Contexto Enferm.* 2008; 17(2):266-72.
 8. Almeida LMS, Falcão IV, Carvalho TL. Avaliação da sobrecarga dos cuidadores de pessoas com esclerose lateral amiotrófica (ELA). *Cad Bras Ter Ocup.* 2017; 25(3):585-93.
 9. Teixeira SCB. Avaliação do estado de saúde dos cuidadores de doentes com Esclerose Lateral Amiotrófica. [dissertação]. Porto: Universidade do Porto; 2017.
 10. Borghi AC, Castro VC, Marcon SS, Carreira L. Sobrecarga de familiares cuidadores de ancianos con la enfermedad de Alzheimer: un estudio comparativo. *Rev Latinoam Enferm.* [Internet]. 2013[citado em 20 maio 2020]; 21(4):1–8. Disponível em: <https://www.scielo.br/j/rlae/a/9ZWMrTjRNnBtnzggK4CGvHp/?format=pdf&lang=es>
 11. Marques AKMC, Landim FLP, Collares PM, de Mesquita RB. Apoio social na experiência do familiar cuidador. *Ciênc Saúde Colet.* 2011; 16(supl 1):945-55.
 12. Mello MP, Orsini M, Nascimento OJ, Pernes M, Lima JMB, Heitor C, et al. O paciente oculto: qualidade de vida entre cuidadores e pacientes com diagnóstico de Esclerose Lateral Amiotrófica. *Rev Bras Neurol.* 2009; 45(4):5-16.
 13. Siqueira SC, Vitorino PVO, Prudente COM, Santana TS, Melo GF. Qualidade de vida de pacientes com Esclerose Lateral Amiotrófica. *Rev Rene.* 2017; 18(1):139-46.
 14. Batista MPP, Miccas FL, Forattore FDS, Almeida MHM, Couto TV. Repercussões do papel de cuidador nas atividades de lazer de cuidadores informais de idosos dependentes. *Rev Ter Ocup.* 2012; 23(2):186-92.
 15. Jenkinson C, Swash M, Fitzpatrick R, The ALS-HPS Steering Group. The european amyotrophic lateral sclerosis health profile study. *J Neurol Sci.* 1998; 160(suppl. 1):122-6.
 16. Guedes RN, Lima LC, Sousa MNA, Toledo MA, Daltro MCSL, Assis SC. Repercussão da esclerose lateral amiotrófica na família. *REBES.* 2020; 10(2):91-7.
 17. Menezes RA. A despedida do corpo : uma proposta de assistência em cuidados paliativos. *Mnemusine.* 2005; 1(2):289-313.
 18. Kovács MJ. Sofrimento da equipe de saúde no contexto hospitalar: cuidando do cuidador profissional. *Mundo Saúde.* 2010; 34(4):420-9.
 19. Oliveira TM. O psicanalista diante da morte: intervenção psicoterapêutica

- na preparação do luto. São Paulo: Editora Mackenzie; 2001.
20. Labaki MEP. Morte. 3a ed. São Paulo: Casa do Psicólogo; 2006.
 21. Calado EF, Lang CE. Psicopatologia fundamental e a morte na doença Esclerose Lateral Amiotrófica. *Psicol Saberes*. 2007; 3(3):15-26.
 22. Quintana AM, Kegler P, Santos MS, Lima LD. Sentimentos e percepções da equipe de saúde frente ao paciente terminal. *Paidéia*. 2006; 16(35):415-25.
 23. Steiner ALF. Profissionais de saúde na relação com os pacientes portadores de Esclerose Lateral Amiotrófica: aspectos psicológicos e de qualidade de vida. [dissertação]. São Paulo: Universidade de São Paulo; 2008.
 24. Gambatto R, Carli FC, Guarienti RF, Silva ALP, Prado AB. Mecanismos de defesa utilizados por profissionais de saúde no tratamento de câncer de mama. *Psicol Am Lat*. [Internet]. 2006 [citado em 20 maio 2020]; (6). Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1870-350X2006000200005&lng=pt&nrm=iso&tlng=pt
 25. Souza MTD, Silva MDD, Carvalho RD. Revisão integrativa: o que é e como fazer. *Einstein*. 2010; 8(1):102-6.

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