

Health education group for people with amyotrophic lateral sclerosis, their families and caregivers

Grupo de educação em saúde para pessoas com esclerose lateral amiotrófica, seus familiares e cuidadores

Grupo de educación en salud para personas con esclerosis lateral amiotrófica, sus familiares y cuidadores

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This is an experience report, carried out from November of 2018 to December of 2019, in a Specialized Rehabilitation Center in Vila Velha, in the state of Espírito Santo, Brazil. It aimed to describe the experience of setting up a multidisciplinary group of health education, with people diagnosed with Amyotrophic Lateral Sclerosis, their families and caregivers. The group called itself "Café com Ela" (Coffee with ALS) and there were eight meetings with the participation of three to nine patients and four to 21 caregivers or family members. The themes chosen were based on the demands of the participants. The group was characterized as homogeneous in regards to the health conditions of its members, and open in regards to the entry into each meeting, and it was always conducted and built in a multidisciplinary way. The group approach in the context of rehabilitation promoted access to information, greater knowledge about Amyotrophic Lateral Sclerosis, emotional support through the sharing of experiences, expansion and construction of social and support networks for coping with the disease.

Descriptors: Amyotrophic Lateral Sclerosis; Health education; Caregivers; Rehabilitation; Rehabilitation services.

Este é um relato de experiência, realizado no período de novembro de 2018 a dezembro de 2019, num Centro Especializado de Reabilitação de Vila Velha, Espírito Santo, com objetivo de descrever a experiência de constituição de um grupo multidisciplinar de educação em saúde, com pessoas diagnosticadas com Esclerose Lateral Amiotrófica, seus familiares e cuidadores. O grupo se intitulou "Café com Ela" e houveram oito encontros com a participação de três a nove pacientes e quatro a 21 cuidadores ou familiares. As temáticas escolhidas se deram a partir das demandas dos participantes. O grupo foi caracterizado como homogêneo quanto às condições de saúde dos membros, e aberto com relação à entrada em cada encontro, sendo sempre conduzidos e construídos de forma multidisciplinar. A abordagem de grupo no contexto da reabilitação promoveu acesso a informação, maior conhecimento sobre a Esclerose Lateral Amiotrófica, apoio emocional através do compartilhamento de experiências, ampliação e construção de redes sociais e de suporte para o enfrentamento da doença.

Descritores: Esclerose Amiotrófica Lateral; Educação em saúde; Cuidadores; Reabilitação; Serviços de reabilitação.

Este es un informe de experiencia, realizado en el período de noviembre de 2018 a diciembre de 2019, en un Centro Especializado en Rehabilitación en Vila Velha, Estado de Espírito Santo, Brasil, con el objetivo de describir la experiencia de la creación de un grupo multidisciplinario de educación en salud con personas diagnosticadas con Esclerosis Lateral Amiotrófica, sus familiares y cuidadores. El grupo se llamó "Café com Ela" (Café con Ela) y se celebraron ocho reuniones en las que participaron de tres a nueve pacientes y de cuatro a 21 cuidadores o familiares. Los temas elegidos se basaron en las demandas de los participantes. El grupo se caracterizó por ser homogéneo en cuanto a las condiciones de salud de los miembros, y abierto en cuanto a la entrada en cada reunión, siendo siempre conducido y construido de forma multidisciplinar. El enfoque grupal en el contexto de la rehabilitación promovió el acceso a la información, un mayor conocimiento sobre la Esclerosis Lateral Amiotrófica, el apoyo emocional a través del intercambio de experiencias, la ampliación y la construcción de redes sociales y de soporte para afrontar la enfermedad.

Descriptores: Esclerosis Amiotrófica Lateral; Educación en salud; Cuidadores; Rehabilitación; Servicios de rehabilitación.

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INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a progressive and neurodegenerative disease associated with loss of upper and lower motor neurons, characterized by weakness of the skeletal striated muscle, with progressive decline in functional capacity, accompanied by dysarthria, dysphagia and respiratory muscle failure¹⁻³.

Recent studies report that the progression of ALS varies between individuals, with the average survival of patients from 3 to 5 years. However, about 10% of cases have a slower progression of the disease and can reach a survival of more than a decade¹⁻³. Thus, the severity of the disease and the uncertainties regarding the course, the worsening of disabilities and the evolution of the burden of care are a cause of great stress for the affected individuals and their families⁴.

The etiology of ALS remains unknown, the pathophysiological mechanisms seem multifactorial with evidence of a complex interaction between genetic and molecular pathways. Evidence suggests several mechanisms involved, the main ones being: mutation in the Cu/Zn enzyme of Superoxide dismutase 1 (SOD1), which can lead to toxicity due to the increase in superoxide; increased glutamate that leads to excitotoxicity with the accumulation of intracellular calcium; accumulation of neurofilaments; mitochondrial dysfunction; activation of microglia and T cells and the presence of autoantibodies⁵. Currently, the immunological component has been the subject of research in the development of the disease, and it is believed that environmental factors and a genetic predisposition are responsible for autoimmunity^{5,6}.

The clinical management of people with ALS is complex and requires a comprehensive and multidisciplinary approach. The general proposals for care are to maximize functional performance and improve quality of life. The focus of care can change as the disease progresses. Therefore, understanding the disease's progression allows professionals involved in the rehabilitation process to anticipate changes in care priorities and prevent possible complications^{1,3}.

People with ALS have multidisciplinary needs due to the complex and dynamic process of the disease, benefiting from individualized and/or group rehabilitation interventions in order to optimize independence, functionality and safety, helping to minimize symptomatic burden and maximize the quality of life⁴.

The World Report on Disability⁷ (2012) describes rehabilitation as a set of measures that help people with disabilities or about to acquire disabilities to have and maintain an ideal functionality when interacting with their environment. Thus, the rehabilitation process involves identifying the person's problems and needs, relating the disorders to the relevant factors of the individual and the environment, defining rehabilitation goals, planning and implementing measures and assessing their effects. The document also points out that educating people with disabilities is fundamental for the development of knowledge and skills for self-help, assistance, management and decision-making.

The rehabilitation of the patient with ALS requires a lot of creativity from the multidisciplinary team to improve and/or maintain the maximum possible functionality, as the disease can evolve quickly and in a diverse manner. In the early phase, physical exercises and use of adapted equipment are indicated. As the disease progresses, medications and resources are indicated for pain control, spasticity, cramps, secretion/drooling management, fatigue, sleep, breathing capacity and communication, in addition to the intensified use of assistive technology⁴.

Advanced disease requires multimodal symptom management, end-of-life care planning and timely use of palliative care. It is important to emphasize that the emotional and psychological aspects, as well as the quality of life, must be taken into account from the moment of diagnosis and throughout the course of the disease⁴.

Education can be understood as a rehabilitation technique, as people with disabilities and their families and/or caregivers are able to improve health and functionality when they are enlightened, oriented and empowered with the acquisition of health knowledge, becoming active partners in the rehabilitation process.

The Ottawa Charter⁸ (1986) conceptualizes Health Promotion as the process of empowering the community to improve the quality of life and health, including greater participation in controlling this process, emphasizing that individuals and communities should have the opportunity to know and control the determinants of their health, being favorable environments, access to information, as well as opportunities to make healthier choices, the main enabling elements.

The group approach provides the patient with the development of personal skills and possibilities for coping with disease⁹. The development of a rehabilitation group with people with Amyotrophic Lateral Sclerosis and their families promotes positive experiences about living a meaningful and shared life, despite serious disabilities, in addition to supporting internal family relationships and the expansion of social networks¹⁰.

Working with groups is an alternative to care practices, which favor the improvement of all those involved, in personal and professional aspects, through the valuation of different knowledge and the possibility of creatively intervening in the health-disease process¹¹.

This work aims to describe the experience of setting up a multidisciplinary health education group, with people diagnosed with Amyotrophic Lateral Sclerosis, their families and caregivers.

METHOD

It is a descriptive study of the type of experience report, which presents, describes and analyzes the experience of setting up a health education group, developed in a Specialized Rehabilitation Center, with people diagnosed with Amyotrophic Lateral Sclerosis, their family members and caregivers. The activity was developed between the end of 2018 until 2019.

The *Centro de Reabilitação Física do Estado do Espírito Santo* (CREFES) is a *Centro Especializado em Reabilitação II* (CERII), qualified in motor and auditory modalities, located in Vila Velha - Espírito Santo. CREFES is a point of outpatient care for people with disabilities and offers the service of prescribing, making and delivering orthoses, prostheses and auxiliary means of locomotion.

ALS patients are assisted by the Adult Neurological Work Unit, which has a team composed of a physiatrist, neurologist and neurologist, occupational therapist, physical therapist, psychologist, speech therapist, social worker and physical educator. In this sector, predominantly post-stroke individuals are treated; however, an increase in the number of patients with the diagnosis of Amyotrophic Lateral Sclerosis was observed at the end of 2018.

This change in the standard of care provided to the multidisciplinary team highlighted the need to develop new rehabilitation strategies, since only outpatient care was not able to answer doubts, uncertainties and fears regarding the diagnosis, treatment and the future, exposed by patients and their families. During the moments of team meeting and case studies, a pattern of repetition of patients' doubts was observed, in addition to the desire to meet other people with the same health condition. Patients and family members suggested the development of a health education group in order to accommodate the demands of ALS patients, their families and caregivers, and the team agreed.

For implantation and effectiveness of the group, patients were initially invited during outpatient care. It is important to highlight that the invitation was not structured in a way that only guarantees adherence to the approach, but envisions the survey of the most relevant themes for them, and their contributions to the planning, execution and development of the

proposal, having an active decision-making process. ALS is a highly disabling disease, therefore, during rehabilitation, respect, encouragement and autonomy must be prioritized in order to promote greater personal motivation and bond building.

An education group for ALS patients, their families and caregivers seeks to encourage people to find resources to deal with the issues of falling ill, the disease, decreased functionality and its effects on their life. From initial meetings between some patients and a multidisciplinary team, the group's name, "*Café com ELA*" ("Coffee with ALS"), was suggested by the former; the choice is associated with the patients' predilection for coffee and the need to face the disease in a mild and relaxed manner.

Initially structured and agreed in a participatory way to the perspectives of Grupo *Café com ELA*, the themes that were constructed as specific intervention projects during the meetings were chosen. The group was characterized as homogeneous as for the health conditions of the participants, and open with regard to the entry of patients, family members and caregivers in each meeting, being always conducted in a multidisciplinary way.

Although the meetings and themes are previously structured, they take place in an interactive way, allowing the involvement of all participants, therefore, it is not just a formal teaching session, always emphasizing the right that each participant has in the exercise of speech, in the exhibition their opinions, their points of view and even the use of silence.

This study is part of the research "*Acompanhamento de Reabilitação do Paciente Neurológico no Centro de Reabilitação Física do Espírito Santo*" approved by the Research Ethics Committee of the Health Sciences Center of the Universidade Federal do Espírito Santo, receiving the opinion number 3,628,685 of 2019 (CAEE: 21020919.0.0000.5060). All stages of the research followed the guidelines of Resolution No. 466/2012 and Resolution No. 510/2016 of the National Health Council.

RESULTS

The *Café com ELA* group was developed between November 2018 and December 2019. During this period, 8 meetings were held, with the participation of three to nine patients and four to 21 caregivers or family members.

At meeting I, held on December 14, 2018, and named "*Getting to know Amyotrophic Lateral Sclerosis*", the themes discussed were: What is ALS; The mechanisms of the disease; The main neurodegenerative diseases; The incidence and prevalence of ALS; What are the causes; Risk factors; What are the symptoms of ALS; What are rare diseases; How is Amyotrophic Lateral Sclerosis diagnosed; How is treatment and rehabilitation done and what are the possible complications of the disease.

During meeting II, held on March 20, 2019, themes related to "*Respiratory Rehabilitation*" were developed, namely: The impairment of ventilatory muscles and pulmonary restriction; Physiotherapeutic approach in Amyotrophic Lateral Sclerosis; Respiratory Support; Benefits of breathing exercises for patients with ALS; Night hypoventilation; Evaluation of respiratory function (spirometry, blood gas analysis, forced vital capacity, peak cough flow, respiratory pressures, pulse oximetry and Capnography); Management of respiratory failure in patients with ALS; Use of invasive and non-invasive ventilatory support; Non-invasive ventilation through a BiPAP device; Air stacking techniques, using Ambu manual resuscitator.

The "*Rights of People with ALS*" were discussed in meeting III, held on May 20, 2019, which addressed: The specific rights of people with ALS and the like; Social and fundamental rights; Service resources available on the network and community support; Ordinances that are intended to care for the person with ALS; Survival records; Home care; FGTS withdrawal; Adapted transport service; Treatment outside the Home; Free pass; Social security rights; Continued Installment Benefit.

At the IV meeting, held on May 30, 2019, the topic “*The mobility of people with ALS*” was discussed, more specifically: Improving the quality of life of patients, families and caregivers; Articulation between patients, family members, caregivers and health professionals to disseminate ALS; Associations and entities working to guarantee the rights of people with ALS, such as the *Associação Brasileira de Esclerose Lateral Amiotrófica* (AbrELA) and the *Associação Pró-Cura da Esclerose Lateral Amiotrófica*.

Still in meeting IV, part of the patients disclosed the annual ALS Awareness Walk developed by AbrELA in São Paulo and showed interest in carrying out a similar movement in the Espírito Santo state, due to the lack of information about the disease and scarce dissemination initiatives. However, due to the reduced number of participants, the short time for dissemination and the clinical and functional conditions of part of the patients, the possibility of walking was ruled out.

The patients and their families then suggested a pamphlet activity to disseminate information about the disease. Having agreed the interest and importance of the group for the development of the activity, patients, family members and professionals engaged in the implementation of the proposal, which was considered the *V Café com ELA* meeting, entitled “Living with ALS learning from them”, completed in June 16, 2019, through an Educational Action at Praia da Costa in Vila Velha-ES.

The choice of location was defined by the proximity to CREFES and by having an accessible structure for people with physical disabilities, due to a City Hall program to promote adapted leisure activities. Through the mobilization and contact of the patients themselves, banners and balloons were made available by AbrELA, and pamphlets and booklets by Pro-Cura da ELA, the action also had the support and participation of the *Associação Capixaba de Pessoas com Doenças Raras* and donation of their own patients and family members to purchase a tent.

Figure 1 - Educational action developed at the V *Café com ELA* meeting. Vila Velha / ES, 2019.

The VI Meeting named “*Care with Food and Swallowing*” July 10, 2019, spoke about: Changes in phonation and swallowing in Amyotrophic Lateral Sclerosis; Dysphagia in ALS; Dysarthria; Dysphonia; Performance of the Speech-Language Pathologist; Compensatory procedures acquired; Myofunctional and learning exercises and techniques that stimulate oral proprioception, postural changes and swallowing maneuvers; Nutritional Intervention in Amyotrophic Lateral Sclerosis; Changes in the characteristics of food (viscosity, temperature, flavor), changes in the volume and rhythm of the presentation, and intra-oral maneuvers; Food Advice on Dysphagia Control; Enteric Nutritional Support.

The “*Use of Assistive Technology Resources in ALS*” was the theme of the VII meeting on April 09, 2019, in which were discussed: The Use of Assistive Technology for patients with Amyotrophic Lateral Sclerosis; The proper prescription; The role of the occupational therapist in the assessment, prescription, guidance on the use and training of devices; Making orthoses of upper and lower limbs; Postural adequacy in a wheelchair; Assistive resources of low and high financial cost; Assistive Resources made available through the Unified Health System; Existing financing for the acquisition of high-cost resources.

The “Caring for those who Care” was worked on at the VIII meeting on November 27, 2019, addressed the themes: Caregiver burden and social support networks; Social support in the experience of the family caregiver; Caregiver's emotional stress; Take care of yourself and the other; The phases of care; Main difficulties found in care tasks; The feelings involved in care; Support groups; Family life and the importance of leisure.

Figure 2. Activities developed during the meetings between *Café com ELA*. Vila Velha/ES, 2019.



The first two images at the top were taken at meeting II on “Respiratory Rehabilitation”. The images at the bottom were taken in the VIII meeting on “Caring for those who care” and in the VII meeting with the theme “Use of Assistive Technology Resources in ALS”.

The number of participants in each meeting of the *Café com ELA* can be viewed through Table 1.

Table 1. Participants by meeting on the *Café com ELA*. Vila Velha/ES, 2019.

Meetings	Participants			Total
	Patients	Family members and caretakers	Professionals	
I	5	5	8	18
II	9	21	11	41
III	4	4	8	16
IV	4	4	8	16
V	8	16	12	36
VI	9	10	9	28
VII	4	7	9	20
VIII	3	5	7	16

DISCUSSION

People with ALS, their families and caregivers must be informed about the disease and its course. It was observed for most patients and their families that the lack of knowledge about the disease was more difficult to deal with than information about what to expect as the disease worsened. Knowledge about the clinical aspects of the disease, reduced functionality and what may happen in the future facilitate the construction, adoption of support measures and the search for adequate assistance in each stage of the disease. Unmet rehabilitation needs can delay rehabilitation, limit activities, restrict participation, cause deterioration of health, increase dependence on assistance from others, and worsen quality of life⁷.

The *Café com ELA*'s meetings provided useful information, tips and coping tools for the promotion of care, stimulating discussion among patients, their family members and health professionals. The group approach in the context of rehabilitation plays an important role for people with ALS and their families, providing social and emotional support through sharing experiences.

A group can help people during periods of adjustment to changes, in the treatment of crises or in maintaining or adapting to new situations, its potential emerges from the possibility of people with similar situations to share common experiences¹¹. Through meetings, participants were able to learn from individuals familiar with the situation they are facing, share ideas with those who have the same challenges, and learn how people with ALS in advanced stages are dealing with problems they may face in the future.

Family members and caregivers of people with ALS experience a series of emotional reactions in this context, feelings of injustice for being healthy while a family member faces the challenges imposed by the disease. Emotional changes due to the increase in daily responsibilities imposed by the accumulation of the caregiver role, in addition to feelings of guilt for not knowing how to deal with the relative's illness, or for reacting with negative thoughts and attitudes. During the meetings, gaps in patients and family members' knowledge, understanding and management of the disease were identified.

Understanding the educational needs of patients allows healthcare professionals to design programs in a format acceptable to patients and their families. Participants reported a better understanding of the disease, the levels of disabilities resulting from the progress of the disease and how to deal with the situation. Through the acquisition of knowledge about ALS, the diversity of symptoms and influence on the reduction of functionality, family members expressed an improvement in the understanding of the behaviors and capacities of people with ALS, and how to deal with, share experiences and support each other in the progression of the disease. and disabilities¹⁰.

A recent study demonstrated that self-perceived deterioration in speech intelligibility and respiratory impairment are directly related to a decline in functional capacity in patients diagnosed with ALS¹. Severe dysarthria, dysphagia, orthopnea and dyspnoea have a great impact on the quality of life of these patients. In this sense, the preservation of autonomy and communication capacity must be promoted by the rehabilitation team¹. The significant number of participants (patients and caregivers) in Meetings II and VI suggest the lack of information on the themes, the impact of functional decline on the patient's quality of life and on the caregiver's burden. The group enhanced the exchanged dialogues, the sharing of experiences and improved communication adaptations, respiratory support and dietary advice to the individual and collective way of life.

During the meetings, the participants became increasingly interested in the topics covered and in getting to know each other, expressing security and confidence in the presence of the other participants in the group. Feelings of loneliness, despair, loss and frustration at having no one to trust, in addition to the perception of incomprehension of the situation experienced, were complaints made by family members of people with ALS before participating in education and support groups¹⁰. The expansion and construction of social and support networks became stronger throughout the program, changing the group dynamics over time. Such experience provided the expansion of the support network and communication among participants beyond the group, through the exchange of contacts, the creation of a virtual group with family members and caregivers, and the mobilization to disseminate information about the disease.

The main obstacles to the participation of relatives of people with ALS in a rehabilitation group are the fear of meeting other people with ALS, the progression of the relative's illness and problems of accessibility and transportation¹⁰. Table 1 shows a variability in the adherence of patients diagnosed with ALS and their family members and caregivers throughout the meetings.

The justification for the variability in participation may arise from denial of the diagnosis, fear of knowing the progression of the disease and its functional decline, problems of accessibility and transportation, a precarious support network in commuting to the service, and socioeconomic difficulties. A positive component was that, due to the impediment of the participation of some patients due to a high degree of dependence and disease progression, some family members were present at the meetings, enhancing their ability to deal with situations inherent to the functional decline and helping other group participants to acquire greater confidence and emotional relief.

Another aspect verified by the multidisciplinary team that impacted the participants' adherence were three patient deaths that occurred in-between meetings. The first death occurred before Meeting II, where the bonds between participants were not well established. However, the other two deaths occurred before Meeting VII when the bonds between the participants were already more secure, emotionally impacting even the professionals involved. In addition, the fear of death is added to these aspects.

One of the themes requested by family members and caregivers was palliative care and terminality. The palliative care approach in monitoring the person with ALS aims to improve the quality of life of patients and relatives/caregivers in the face of an incurable and potentially fatal disease, relieving pain and other distressing symptoms, affirming life and considering death as a normal condition of the existence process, integrating psychological and spiritual aspects, and offering a support system to help families and caregivers to deal with the challenges before and after death¹². Despite the extreme relevance of the theme, the multidisciplinary team assessed that it was not the most opportune moment for discussing the

theme, due to the precocity of the constitution of the group and the lack of maturity and elaboration of the possibility of death among the participants.

Due to the progressive nature of ALS, a creative approach to the rehabilitation paradigm must be adopted, which requires the involvement of therapists familiar and experienced with the complexities of the disease¹³. *Café com ELA* enabled the exchange of knowledge and experiences between health professionals with different degrees and knowledge, providing opportunities for communication and teamwork, the standardization of concepts among professionals, constituting a space for permanent health education. In addition to favoring the construction of therapeutic alliances with patients and their families, to meet immediate and future needs.

CONCLUSION

Rehabilitation services need to be constantly improved to suit the needs of people with Amyotrophic Lateral Sclerosis. Outpatient follow-up is often not able to meet all the demands of patients and their families, leading to a low level of knowledge about the disease and misinterpretations about decreased functionality and its effects on their life.

The group approach in the context of rehabilitation and participation in the program, provided a learning environment for people with ALS and their families, promoting emotional support through sharing experiences, expanding and building social networks and supporting coping disease.

In relation to the limitations found, were identified issues of planning and organization of the flow of care, since the approach to health education was new as an integral part of the permanent actions of the Adult Neurological Treatment Clinic of CREFES. As a future perspective, it is suggested to measure the level of knowledge of the participants through assessment instruments, enabling the quantitative measurement of changes during the participation in the group.

In turn, it is expected that the experience presented here will stimulate the practice of health education in the context of rehabilitation, in other locations and realities, in particular, its applicability in the treatment of people with Amyotrophic Lateral Sclerosis.

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CONTRIBUTIONS

Crystian Moraes Silva Gomes and **Jonaina Fiorim Pereira de Oliveira** participated in the design of the study, collection and analysis and writing. **Ana Raquel Silva** contributed to the study design and review.

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