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Case reports

The practice of the art of clowning by a person with aphasia: a case report

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ABSTRACT

This study addresses the effects of the art of clowning on the quality of life and well-being of a woman presented with aphasia and depression. She was discharged from individual Speech-Language Therapy due to improved language skills, but she continued expressing emotional complaints associated with communicative situations. The participant joined Palhafasia, a community project that welcomes aphasics for group clowning sessions. She participated for six months in once-a-week meetings that lasted three hours each. The comparison of pre- and post-intervention measures detected improvements in her quality of life, including communication and subjective well-being of the participant. This innovative case study provides a preliminary contribution that must be further investigated. The study points to the potential benefits of the practice of clowning to promote quality of life and well-being of people with aphasia who suffer from depression.

Keywords: Aphasia; Quality of Life; Art

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INTRODUCTION

Aphasia is a language disorder that results from brain damage. Most people with this condition are older adults (aged 60 and over) and the number one cause of aphasia is stroke, which is also the main cause of disability and mortality in Brazil[1]. As early treatment of stroke improves in Brazil, the number of survivors with aphasia increases[2]. This means that investment in rehabilitation is urgent. This concern expresses itself in the publication of the national guidelines for the rehabilitation of people who survive stroke[3], and the efforts to mitigate the social consequences of aphasia must increase.

Frustration during communication, social isolation and stigma reduce the well-being of people with aphasia[4]. The incidence of depression and disability are high in Brazilian stroke survivors and associated with communication deficits and low quality of life[5]. Participation in groups alleviates the effects of these factors and improve the quality of life of Brazilian stroke survivors[5]. These findings corroborate the research that suggests that therapy should be focused on daily life changes related to communication and the well-being of the person with aphasia as the frequency of social contact of people with aphasia is related to their quality of life[6,7].

In recent decades, integrative and complementary practices have been included in Brazilian public health policies, which allow public healthcare centers to offer therapeutic options such as integrative community therapy and music therapy[8]. The adoption of therapeutic approaches that include goals of social inclusion and expression through art for the person with aphasia can and should be a fertile field for public services to the population. However, the current challenges faced by the Sistema Único de Saúde (SUS - Unified Health System) indicate that these models of care are at risk and need support and strengthening[9]. Considering the relevance of promoting the quality of life of people with aphasia, it is important to define the role of different services offered to this population, reflect on the importance of referrals to groups that promote empowerment through art and culture, as well as plan the process of continuous care in different services, considering the importance of social inclusion[10].

Theater encourages people with aphasia to use gestures and facial expressions to increase confidence during communication[11,12]. In Brazil, the Performing Arts have been particularly relevant as means of expression for adults with aphasia[13-15]. Dance groups have also been developing a deep understanding of inclusion of people with disabilities[16]. Different from recreational models, these approaches aim to provide active body expression and authentic expression of the participants' individuality, in addition to elements of the Brazilian culture. Inclusive performances demonstrate that humor is a critical element capable of achieving public engagement and understanding of the participants' view of the social conditions they face[16].

The therapeutic role of humor and clowning in health

Humor is increasingly valued in the health context and a catalyst for social transformation. Laughter is valuable in conversations with people with aphasia and shared humor is often experienced in social groups of people with aphasia[17,18]. In the scenario of appreciation of humor in the health area, the art of clowning has significantly increased, especially regarding the presence of the visiting clown in different environments, such as hospitals and geriatric centers.

Clowning in therapeutic contexts is defined as the implementation of clown techniques derived from the world of circus and theater with the purpose of improving the quality of life of the population[19]. Most publications on the therapeutic effects of clowning focus on the visiting clown or on clown visits. In Brazil, clown visit programs have become popular, especially when interacting with children in hospitals[20]. However, research shows that clown visits are also well received by adults[21]. People with dementia who are visited by clowns experience an increase in non-verbal expressions that show satisfaction and joy[22]. The interaction with clowns in the health context demonstrate that the relationship established between therapeutic clowns and people with dementia is rich and reciprocal[23]. However, health research still focuses almost exclusively on hospital and geriatric visitation programs. In Brazil, the active practice of clowning by people with intellectual disabilities has been previously investigated and has shown great potential[24].

Considerations about the practice of the art of clowning by a person with aphasia

To date, there are no publications on the effects of active clowning by adults with neurological disorders. It is important to understand the essential elements of the art of clowning to understand the beneficial potential of this activity for the person with aphasia.

Learning how to be clown is learning how not to act. The clown is not a character, but an extension of the naive human aspects of each person. The clown apprentice is asked to communicate creatively and not to be constrained by classifications such as ‘right’ or ‘wrong’. Therefore, communicative diversity is always welcome, which puts the individual in contact with one’s own way of expressing themself. One of the most transformative aspects of clowning may be precisely the fact that the clown is not focused on “fixing” anything, but rather on creating something from the exposure of their human “flaws”. Participation in such a context can bring about a change in the way of conceiving one’s own experience of accepting one’s vulnerabilities and promoting the pleasure of knowing oneself[24].

In clown practice, social rules change radically, with functional strategies and personal communication styles being highly valued. The playful context seems to increase the participants’ safety to express themselves in different ways than usual. In a collective meeting of clown practice, the clowns communicate much more through facial and body expression and their verbal expression allows ‘weird’ and different ways of speaking than the one expected. These are valued as authentic expressions. Sharing emotions and exposing what society understands as failure is desirable to clowns, which can be considered a release from conventions that create stigma[25].

The present case study takes into consideration reflections on the quality of life of the individual with aphasia and the importance of practices that promote art in community, particularly the art of clowning. The study describes the case of a woman with predominantly expressive aphasia and a clinical diagnosis of depression. Improvement in language was observed after 6 months of individual speech therapy in the outpatient clinic of a highly complex public hospital. The persistence of emotional complaints associated with communicative situations led to assisted hospital discharge, which involved a stage of adaptation to social inclusion services outside the hospital. Upon participating in the social group for people with aphasia, the rehabilitation center then invited her to participate in *Palhafasia*. It is an extension project that welcomes people with aphasia for clowning sessions in group. Upon choosing to participate exclusively in the *Palhafasia* group, the participant gave consent to be part of the present case study that aims to report the effects of this intervention throughout the course of six months.

CASE PRESENTATION

This is a mixed (qualitative and quantitative), observational, interventional, and analytical, descriptive, longitudinal case study[26]. It was approved by the Research Ethics Committee of the Psychology Institute with the Federal University of Rio Grande do Sul - UFRGS (protocol No 29162), Brazil, and it is part of a larger project registered on the *Plataforma Brasil*. The participant signed the free and informed consent form (IC) in which she was informed about the procedures and details of the research.

Selection criteria of the case

The following criteria were respected when choosing the case: 1) medical report (provided by a neurologist) of the ischemic stroke on the left cerebral hemisphere, confirmed by computed tomography; 2) stroke having occurred at least 6 months ago (period of spontaneous recovery of the brain); 3) Brazilian nationality and origin, monolingual speaker of Brazilian Portuguese, 4) minimum of four years of schooling; 5) absence of uncorrected vision and hearing difficulties; 6) speech therapy diagnosis of predominantly expressive aphasia with complaints related to quality of life; 7) not undergoing individual speech therapy at the time of the study; and 8) not participating in social group meetings.

An important observation regarding the participant’s choice in not receiving other types of therapy is that the participant spontaneously decided to give up other services. When discussing assisted discharge from individual speech therapy at the hospital, L was invited to participate in the social group sessions organized by the team at the university. On the same occasion, L was invited to join the art of clowning project. After experiencing a session, as L worked as a caregiver, she argued that she would only have one shift a day per week for extra activities. It was then that L clearly stated that she chose to participate only in the art of clowning project.

Case description

L is a 67-year-old woman with incomplete elementary education who had previously worked as a cook. She had a stroke in February and another one in April 2016. After the second stroke, the symptoms of predominantly expressive aphasia appeared. When she was referred to speech therapy, the clinical diagnosis of depression was already recorded in her medical record. Despite respiratory problems and verbal disfluency, L continued to work as a caregiver for an elderly couple after the VBD. L is a person who takes good care of others, but reports difficulty taking care of herself. She has difficulties adopting healthy eating habits and there is a recurrence of smoking and alcoholism, despite guidance/instructions and regular medical care. L has a partner, but she says he also has health conditions that require care. L has no children, does not live with any family members, and her mother passed away a few years ago.

Most of L's language skills are currently within the expected range for her age group and education, except for oral comprehension of sentences, for which Z-score indicates an alert for neuropsychological deficit. Results of the Montreal-Toulouse battery subtests are shown in Figure 1. Scores between -1.0 and -1.5 indicate an alert for neuropsychological deficit and scores between -1.6 and -2.0 indicate moderate to severe deficit.

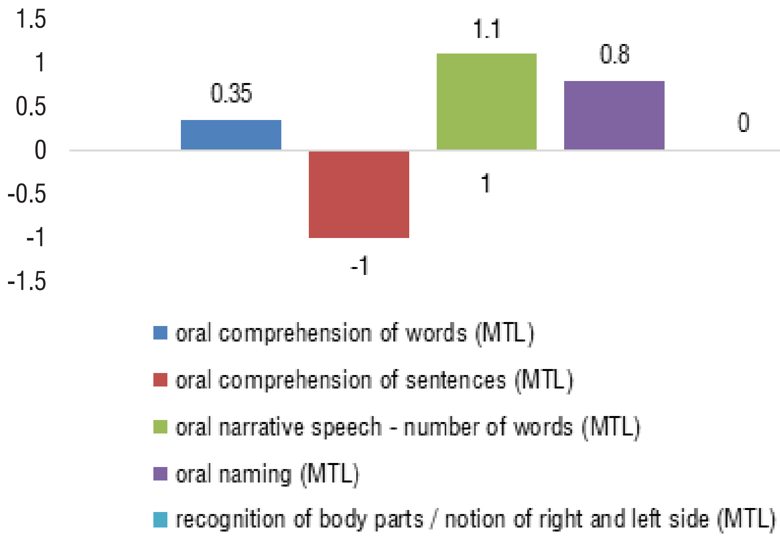

Figure 1. Characterization of the linguistic profile (Z-scores)

Palhafasia clowning group

The practice of the art of clowning took place in the group named *Palhafasia*, an extension project that welcomes people with aphasia and undergraduate students. The meetings involve games which gradually pave the way for emotional expression and individual improvisation or in pairs. During the meetings, the group members start using different means of communication, paying special attention to the expression of the body, face, and gestures. When verbal difficulties arise, such as hesitations, anomies and paraphasia, these are considered interesting situations for clowns, who are encouraged to seek creative solutions to express themselves. Each member is encouraged to discover his/her clown and the interaction with the group, which acts as an audience at the meetings, is a relevant aspect. The clown shares attention not only with his stage partner, but also with the audience. Thus, working with communication covers aspects such as empathy, initiative, reciprocity, and expression of humor.

The meetings of the *Palhafasia* group are organized in a way as to make a gradual transition to the role of a clown. All participants are reassured about the safety of sharing emotions and activities are designed to support their understanding of the art of clowning. The activities are creative, but are repeated weekly; therefore, they have a predictable and progressive effect from week to week. Tasks provide clues that elicit immediate responses rather than free evocation, usually through imitation as a way of presenting a model of action. The structure of the sessions follows a gradual order: 1) fun warm-up games; 2) dramatization of funny activities; 3) Transition to the clown using music, costumes, a hat and the clown nose; 4) Improvisation activities encourage participants to be spontaneous, while improvising acts based on simple scenarios and instructions. The facilitator provides instructions according to the initiatives and needs of each participant. Improvisation activities evolve from being alone to sharing attention with the audience (group) using an object, progressing towards the interaction with a scene partner. Finally, the sessions end when all participants sit in a circle and are encouraged to share feelings and thoughts related to the experiences. During all the activities, music is present, and the environment ensures affective safety and care. The experience of this six-month cycle was concluded with the presentation of an open rehearsal for the audience composed of members of the conversation group and students from the speech therapy program to present the short acts by two or three clowns.

Instruments

The data collection of the study occurred from March to September 2017. Subtests of the Montreal-Toulouse battery for language assessment (MTL-Brazil)[27] were used to obtain the linguistic profile (for the purpose of characterizing the case). The subjective well-being scale (SWBS)[28] was administered to obtain subjective well-being measures (pre- and post-intervention). The scale is composed of 62 items, of which 21 items assess positive affect, 26 items assess negative affect and 15 items assess satisfaction with life. The scores in the subjective well-being scale (SWBS) range from 1 to 5, in which 1 means “not at all” and 5 means “extremely”. The higher the score for positive affect and satisfaction with life, the better is the individual’s subjective well-being. For the assessment (pre- and post-intervention) of quality of life, the Quality of Life Scale in Aphasia was translated and adapted to Brazilian Portuguese in a study that presented reference data[29]. This scale can be administered to people with different degrees of impaired expression and understanding. Both the subjective well-being scale (SWBS) and the SAQoL-39 quality of life questionnaire were administered before the beginning of the clowning intervention and at the end of the intervention period for comparison.

Regarding the qualitative research data, observations were made by the team during the process. After the intervention period, an open interview was conducted with the purpose of listening to the participant and obtaining data on her perception of the intervention.

RESULTS

There was an increase in feelings of positive affect as well as a decrease in feelings of negative affect, but this does not seem to mean considerable improvement in life satisfaction (see Figure 2). When comparing the quality of life (QoL) data collected before and after the end of the clowning intervention, there was a significant improvement in terms of communication aspects as well as increased energy for daily activities (energy score). The psychosocial aspects investigated showed improvement, although less significant. The participant showed no improvement in the physical aspects (see Figure 3).

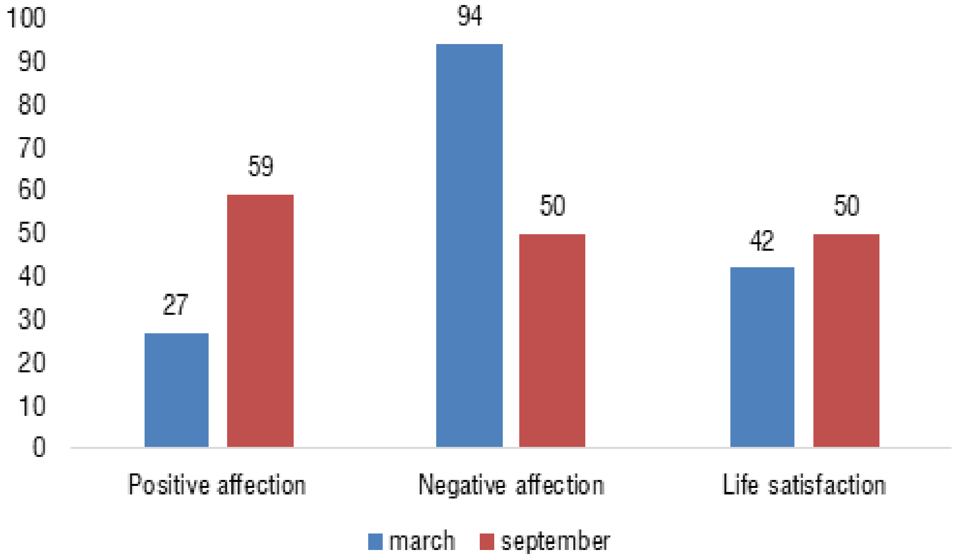

Figure 2. Comparison of the improvement of subjective well-being using the SWBS before and at the end of the analysis of the art of clowning sessions

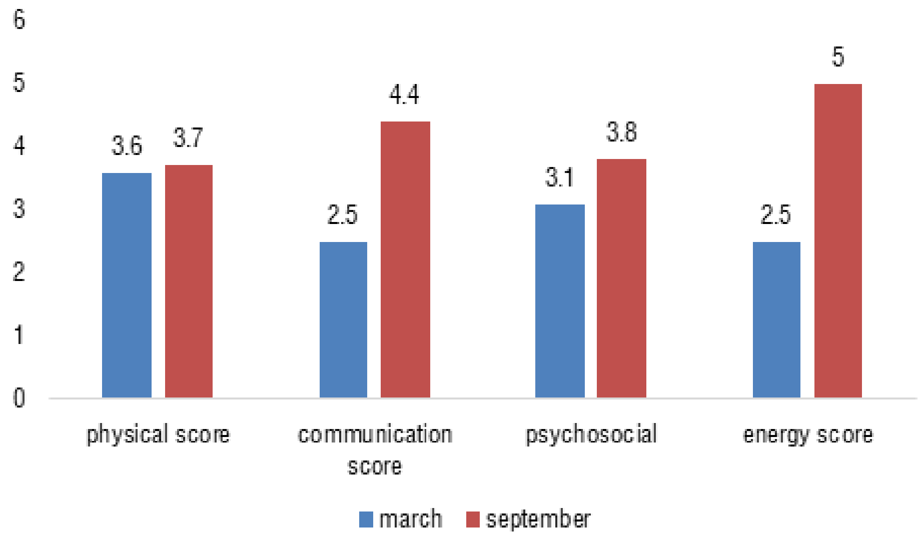

Figure 3. Comparison between the administration of the SAQOL-39 quality of life questionnaire administered before and at the end of the clowning intervention

Interview after the intervention period

Interviewer: *What do you feel when you come to the project?*

L: *<u>I like to do this</u>, I feel good. <u>When I don't come, I miss it</u>.*

Interviewer: *um-hum ... but why? Why is it different here?*

L: *I like being here, I like to talk, I like to watch you talking ... I feel good, it's because I don't, I don't go anywhere else, I just go from home to work and from work to home, I don't going anywhere anymore since my mother passed away, not even to my mother's house, I went back, I never see my niece, I never do anything ... it's been a year since I haven´t been. Before I always visited once a week, I went to XX (name of the city) and stayed all day and never been again, I go from home to work and I only come here, so that makes me feel good. <u>And when it is Tuesday at six o'clock in the morning and I'm already up because I have to leave, I'm already thinking about the time I leave work to come here. I just feel good, I feel really good.</u>*

Interviewer: *What is it about the project that you feel good about?*

L: *The fun.*

Interviewer: *Hmm.*

L: *<u>The fun.</u>*

Interviewer: *And does that change anything?*

L: *I can't explain it ... but I like it.*

Interviewer: *And what happened to you during the process of discovering clowning?*

L: *Ahh, it was very good! <u>I had a lot of fun and played with my boss at work</u>.*

I called out to him 'come Quindim de Iaiá' (laughter). And now every now and then I play with him, and I ask him 'so what's up today?'. I liked it a lot, it did me good.

Interviewer: *Um-hum, good! And that whole process of creating your costume, dressing up, putting on makeup, what do the activities we do mean to you?*

L: *Ahh, it changes a lot, I had a lot of fun, I really liked it! <u>It makes me forget many things ... many things ...</u>*

Interviewer: *Does that mean you forget things when you wear that outfit? Put on your clown nose ...*

L: *<u>I feel like someone else</u>. I did that letter thing, which I liked, that thing of trying to guess.*

Interviewer: *Um-hum.*

L: *<u>It seems that we are actually doing that</u>, I felt that, yeah, especially when I did it at the theater. And when I rehearsed here, when I put on my clothes, I liked them, I felt something else.*

Interviewer: *What else did you feel?*

> L: *I can't explain for sure, but I felt more at ease. Calmer, more at ease, I felt at ease. When I was a child, I was in the school theater where I studied, I studied at a nun's school when I was a child, and I had already participated in theater and I never forgot it.*

Observations of the team

During the clowning meetings, L demonstrated motivation and an increasingly spontaneous playful attitude. In the moments of improvisation, L's clown gradually revealed herself, first with seriousness and shyness, then with greater resourcefulness as she became a kind of gypsy with a serious face. L proved to have a talent for costume design and often helped with sewing emergencies in the clothing of other clowns. However, she was most dedicated to designing and sewing the details of her own costume. Her costume included a gypsy turban adorned with chains and a red rose. She chose to wear a dress and bolero in discrete color tones. Her clown revealed a taste for putting on makeup.

The name she chose for her clown evoked the affectionate nickname used by her to call her "boss", a man with dementia who she takes care of. Often during improvisation, L called out her clown's name as a kind of "battle cry", which seemed to evoke a powerful magical ritual addressed to all participants. Her clown gradually revealed smiles and tender looks, mixing melancholy, wisdom, energy and cunning. Her final act was created from improvisations and ideas discussed in groups. It was presented in a theater as an open rehearsal, along with the other members, with the members of the aphasia social group, and students of the speech therapy program as spectators. The motto of her performance was "spiritual service" offered to another clown. In this act, she offered a taro session that took place between cheating and scandalous revelations about the client's love future. The audience responded with attention and laughter.

DISCUSSION

The finding of an increase in the subjective well-being and quality of life of the participant after practicing the art of clowning indicates the potential benefits of this type of intervention for people with aphasia. Evidence found in the literature also points out that the theater is a medium that can favor the self-esteem of people with aphasia and their performance in daily activities[11,12,15].

The measures of well-being and quality of life proved to be useful for examining the possible effects of the art of clowning. The SAQoL-39 instrument provides important data on the quality of life of people with aphasia, particularly regarding the aspect of daily life communication. A particularly striking data obtained with this instrument revealed that improvement in communication was significantly outstanding. This is a particularly relevant result for reinforcing the importance of these interventions in the field of speech therapy.

The literature shows that clown visits have been well accepted by adults and the elderly, including the improvement in communication of people with dementia[23]. However, the clown performances have almost exclusively been reported as a process in which only therapists experience "being a clown". The present project proposes the active experience of the art of clowning, which has already been recognized as a powerful therapeutic process[24].

The increase in energy scores on the quality of life scale is also particularly relevant for understanding the effect of the practice of the art of clowning on the life of this participant with aphasia and a clinical diagnosis of depression. The quality of life scale showed improvement, although less significant, in the psycho-social aspects probably because, in this case, broader social changes would be required to affect the other social contexts of the participant. The participant did not show improvement in physical aspects, which may be related to the fact that she continues to experience breathing difficulties, since these symptoms were observed throughout the intervention period. Here again, the importance of developing strategies that encourage self-care to promote physical well-being is confirmed.

The results of increased positive affection and the minor improvement in satisfaction with life seem to be similar to the experience reported in an Australian study that investigated the effects of clown visits on the quality of life of people with dementia[21]. The researchers of this study observed important differences in the response to a quality of life scale and in the perception of moments of positive affection during clown visits. While the scale did not capture changes in the participants' quality of life, the videos analyzed by the researchers showed positive changes whenever the participants met the clowns. The responses in the interviews also demonstrated that the intervention brought joy to their lives and reduced moments of sadness. The researchers argued that the therapeutic effect of the clown visits was to promote moments of quality of life for the participants and reduce the occurrence of feelings of sadness.

The complexity of the challenges faced by a person with aphasia requires a wide range of social resources to build greater satisfaction with life. Regarding health promotion, interdisciplinary efforts are needed to enable more profound changes in their reality. In the case of L, from the moment she started individual speech therapy, she was referred to psychotherapy at the university clinic. However, she did not adhere to treatment, claiming that she did not like to talk about her personal problems. Likewise, she also did not adhere to the support groups for nutrition education and smoking cessation. In addition to claiming that she could not be absent from work, probably L did not feel at ease in interventions that require the exclusive use of verbal communication. In addition, L might feel more comfortable in inclusive contexts, which include the presence of other people who have communicative difficulties/limitations. Often the team explicitly deals with self-care issues in the social group, but the warm-up activities in *Palhafasia* inspire self-care in a playful way. The fact that L continued to be part of the *Palhafasia* group denotes that being part of this group is considered a legitimate intervention and chosen by the participant.

L's preference for clowning compared to individual speech therapy and the participation in the social group is noteworthy. It shows the importance of offering activities centered on the individual and integrating the objectives of language recovery and promotion of quality of life and well-being.

The clowning experience seems to offer unique elements that are necessary in the participant's life. L's testimony in an interview sheds some light on how the work with the art of clowning has affected this woman with aphasia. L says she looks forward to the day and time of the clowning meetings. She seems to see her participation in the group as a support network similar to the family network, something that replaces the interaction with her mother. In addition, the participant's comment seems to illustrate how playing became part of her daily life outside *Palhafasia* when she mentions the games with her boss.

During the interview, L reveals that the experience of dressing up and dressing like a clown amuses her, makes her "forget about many things". Although she does not directly address the topics that she seems to want to forget, her participation in the project may be a therapeutic alternative that makes her feel "at ease". She recalls the tarot game and the guessing game of her clown, who plays a powerful gypsy. She confides the feeling of experiencing the scenes of her clown, especially on the day of her presentation at the theater. The theater presentation seems to be perceived as a singular element that grants power and expression.

In short, L's statements reveal the importance of the social reception of the clown. In this context, elements such as fun and access to the world of imagination can be essential. Negative experiences seem to be supplanted by the clown's permission to live and feel clowning. In contrast to the difficulty that L presents in taking care of herself, her clown is powerful and well taken care of, which can be observed by her care with costumes and makeup. This suggests that clowning can be used as a key to the development of self-care. Finally, reliving the experience of theater in childhood also seems to have rescued a happy child memory. As stated by Pendzik et al.[30], one of the main characteristics of the clown dynamics is imagination. The clown's imagination is a healthy psychological resource that helps to promote beneficial attitudes and thoughts. The clown state provides openness (which makes the person *feel at ease*), enables other visions (feeling *something else, being someone else*), and the state of attention facilitates contact with the present (the feeling of *doing it for real, experiencing it*) [24,25].

Although the personal testimony highlights important aspects about the mechanisms that may be involved in improving well-being and quality of life, the brief interview conducted in this study is not sufficient to demonstrate the effect of the clown practice alone. Furthermore, the limitation of the study could be that fact that the interviewer was the team coordinator. However, the administration of the scales was carried out by other team members and these instruments do not address issues related to the intervention, which prevents response bias.

CONCLUSION

In the present study, the practice of the art of clowning benefited the participant's well-being and quality of life by improving energy and communication. These preliminary data are promising; however, further research on the effect of theatrical practice as well as the art of clowning is required. This case study is the first step towards carrying out a broader study with a future group of clowns who will join the project.

Interdisciplinary activities between the areas of health and the performing arts and circus are welcome, particularly due to the rich exchange of learning that can be established, and humanizing practices in the health area.

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