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Experience Report

Civil society organizations in times of pandemic: a report from the concept of collective occupational reconstruction

Organizações sociais civis em tempos de pandemia: um relato a partir do conceito de reconstrução ocupacional coletiva

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ABSTRACT

Introduction: This article reports collective actions developed by participants of two Civil Society Organizations representing people diagnosed with multiple sclerosis, located in southern Brazil, during the period of the COVID-19 pandemic. **Objective:** To highlight the strategies and actions that comprised part of the collective occupational reconstruction process of the Civil Society Organizations. Therefore, it describes the results of collective processes, based on reflection on the phenomena observed by the authors. **Method:** This is a descriptive, qualitative research based on an experience report. The practices occurred remotely during the pandemic period (March to December 2020). **Results:** It was found that social media platforms contributed to maintain the collective occupations of the group, facilitating the process of collective occupational reconstruction of Civil Society Organizations. Among the used tools, instant messaging and video calling applications stood out, which facilitated the development of collective practices, thus minimizing the impacts of physical distance. **Conclusion:** Social media platforms are powerful resources to maintain collective action and occupational reconstruction processes.

Keywords: Social Organization, Pandemic, COVID-19, Activities of Daily Living, Community Participation.

RESUMO

Introdução: Este artigo relata ações coletivas desenvolvidas por participantes de duas Organizações Sociais Civis representantes de pessoas com diagnóstico de esclerose múltipla (EM), localizadas na região Sul do Brasil, durante o período da pandemia de COVID-19. **Objetivo:** Evidenciar as estratégias e ações que

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constituíram parte do processo de reconstrução ocupacional coletiva das Organizações Sociais Civis. Portanto, descreve os resultados de processos coletivos a partir da reflexão sobre os fenômenos observados pelas autoras. **Método:** Trata-se de um trabalho descritivo, do tipo relato de experiência, com a abordagem qualitativa. As práticas ocorreram de forma remota durante o período da pandemia (entre março e dezembro de 2020). **Resultados:** Verificou-se que os dispositivos de mídias sociais contribuíram para a manutenção das ocupações coletivas do grupo, facilitando o processo de reconstrução ocupacional coletiva das Organizações Sociais Civis. Entre os dispositivos utilizados, destaca-se os aplicativos de mensagens e de videochamadas, que facilitaram o desenvolvimento das práticas coletivas, minimizando os impactos negativos do distanciamento físico. **Conclusão:** Os dispositivos de mídias sociais apresentam-se como recursos potentes para a manutenção do fazer coletivo e nos processos de reconstrução ocupacional.

Palavras-Chave: Organização Social, Pandemia, COVID-19, Atividades Cotidianas, Ação Comunitária para a Saúde.

Introduction

Collective occupation and occupational reconstruction

According to Townsend (1997, p. 4), "occupation is the active process of living: from the beginning to the end of life"; therefore, our occupations include all the active processes we engage in to take care of ourselves and others. Still according to Townsend, occupation has a transformative potential that refers to the opportunities for individuals to choose and engage in occupations for the purposes of directing and changing either personal or social aspects of life. Collective occupation is defined as any occupation that is engaged in "by individuals, groups, communities and/or societies in everyday contexts" (Ramugondo & Kronenberg, 2015, p. 17) with the aim of promoting equity and social organization through shared doing. The results of human action in a collective occupation are not given by the sum of the actions of the individuals who participate in it, but by the dynamic of their union, which is linked to experiences of belonging and connectivity (Ramugondo & Kronenberg, 2015). Individuals occupy themselves with and develop activities that are directly associated with doing "for" and "with" the collective, so that each one's doing is a part of the other's doing. Unlike occupation centered on individualism, where the focus of action is on individual self-interest and doing it alone (Gerlach et al., 2017) collective occupation is related to the desires of the collectives, and can emerge from the desire for change, generated by a feeling of discomfort in the face of social injustices (Rudman, 2013). Frank (2012) and Frank & Santos (2020) present the occupational reconstruction theory conceptualizing occupation as transformative activities that involve reflexive processes in the course of corrective and/or creative actions that reorganize and reconstruct the world in which we live. The occupational reconstruction theory combines the key elements that enable collective and cooperative action by individuals to reorganize their occupations and solve problematic situations based on a common desire for change.

According to the aforementioned authors, occupational reconstruction is a transformative social action that calls on our "basic human capacities for self-organization and cooperative action to solve problems creatively" (Frank & Santos, 2020, p. 1). Occupational reconstruction occurs when people feel that there really is no choice but to act to transform a situation (Frank & Muriithi, 2015). From the desire to transform a situation, individuals transform, reorganize and/or reconstruct their occupations (Frank, 2012). The occupational reconstruction theory explains social transformation as part of the philosophy and knowledge base of "occupation" with a focus on collective action as an expression of a shared desire to improve a situation (Santos et al., 2020).

From this perspective, with the COVID-19 pandemic, people were challenged to find new ways of relating and carrying out their occupations, and had to adapt their routines and everyday activities to different contexts of human activity (Muñoz, 2020). With the physical distancing measures adopted to provide biosecurity conditions and prevent illness, people were impelled to creatively transform their everyday lives to maintain social participation at the individual and collective levels (Frank & Santos, 2020). With the pandemic, the economic inequality in Brazil was evidenced by the reduction or unavailability of public services, as well as by the failure of population protection agencies (Frank & Santos, 2020). A study conducted by the "Nossa Causa" Civil Society Organization addressing the impacts of the COVID-19 pandemic on Brazilian Civil Society Organizations shows that the most evident impacts that have received greater attention in the media refer to services rendered by government agencies and private for-profit institutions. On the other hand, according to "Nossa Causa", nonprofit Civil Society Organizations have also been impacted and are facing the risk of interrupting their activities because of suspension of government funding and instability in fundraising from individuals and legal entities (Nossa Causa, 2021). The combination of these two circumstances accentuated the helplessness of the population that was already in a vulnerable situation due to the political and economic crisis of recent years.

Nonprofit Civil Society Organizations are private entities formed from the association of socially vulnerable and at-risk individuals (Brasil, 2014). As entities established to benefit the public good, Civil Society Organizations develop action strategies as social and political units (Brasil, 1999). These organizations are instruments that facilitate the recognition of problems and actions to be developed to solve them. Civil Society Organizations foster political participation and act as negotiators between governmental or private organizations, especially seeking to overcome conflicts and/or inequities that interfere with the everyday life of the population. In a study addressing actions developed by parents who are members of a Civil Society Organization that seeks to improve the quality of life and health of their children and family members, Núñez et al. (2019) expand the understanding of COs as a way of overcoming social injustices, based on an entity of this nature. They reveal collective occupation as "a device of force and struggle" through which participants unite "against hegemony to fulfill their purpose of autonomy, freedom, and emancipation" (Núñez et al., 2019, p. 10). Supported by the reflection of Kantartzis & Molineux (2017), we understand that Civil Society Organizations can be considered spaces for the production of life where human activity can be organized and reorganized based on individual engagement in

COs, since the everyday life of Civil Society Organizations is marked by actions and activities that are selected, programmed, and developed collectively. However, what role do these entities play in contexts where the collective is surprised by the imposition of restrictive measures such as the social distancing of individuals?

This experience report starts from this questioning to assess the strategies and actions developed by two Civil Society Organizations formed by people with multiple sclerosis (MS) to overcome the difficulties imposed by social distancing during the COVID-19 pandemic. This study aims to highlight the importance of collective occupational reconstruction developed in spaces of social participation.

Characterization of the Study Participants: the Tortuous Paths of Civil Society Organizations

This experience report describes the tortuous paths taken by two Civil Society Organizations formed by people with MS located in the southern region of Brazil. Before presenting these associations, we would like to point out that the adjective "tortuous" presented here is based on the understanding that both institutions have traveled winding, steep and difficult roads. Both entities are characterized as Civil Society Organizations recognized by the Government as of benefit to the public good and are registered in and linked to the Brazilian Association of Multiple Sclerosis (ABEM) and the Multiple Sclerosis International Federation (MSIF). These Civil Society Organizations are managed by people who, after being diagnosed with MS, voluntarily dedicated themselves to develop and carry out actions capable of giving voice to the needs of the population they belong to and represent. Both Civil Society Organizations authorized the disclosure of the information presented here by signing an Institutional Authorization Form. Aiming to preserve the identity of these institutions, the codenames *Lírio* (Lily) and *Dália* (Dahlia) are used for organizations A and B.

The *Lírio* civil society organization : a path shared with occupational therapy

After receiving a diagnosis of MS, a group of people created the *Girassol* (Sunflower) Group in 2000, and started meeting monthly thereafter. The meetings aimed to inform the participants about MS. With the voluntary professional support of a neurologist, in these meetings, the participants shared their anxieties, uncertainties and discoveries about MS, which was still a little-known disease at that time (Associação de Portadores de Esclerose Múltipla de Santa Maria e Região, 2021). Over the years, professionals and students from different areas of knowledge participated in the meetings of the *Lírio* Group, organizing actions with the objective of obtaining results for academic research. After a few years, the participation of the academics was reduced, which had repercussions on the Group's actions.

Eight years after the *Lírio* Group was created, the first author, then an Occupational Therapy newly graduate, was informed about the dispersion of the Group, caused by lack of people willing to coordinate the activities regularly carried out. Although little experienced in coordinating groups and with scant knowledge about MS, she managed to get the Group to be invited to participate in an university extension project in partnership with the Occupational Therapy graduate studies program at the Franciscan

University (UFN). Group participants were encouraged to play a leading role in relation to their own history and the construction of a collective space. Motivated by the desire to overcome the stigmas associated with MS, the group members began to dedicate themselves to prepare information campaigns about MS. Six months after the beginning of the project, moved by the interest in obtaining greater social representation, the *Lírio* Group started developing activities to organize a social entity, creating the OSC (Associação de Portadores de Esclerose Múltipla de Santa Maria e Região, 2021).

Officially established in August 2009, the *Lírio* Civil Society Organization was founded by people with a diagnosis of MS and healthcare professionals. Currently, it is dedicated to promoting social change through information campaigns, scientific events on MS, and the inclusion of people with MS in the National Health Policy for People with Disabilities (PNSPD) and the National Policy for the Integration of Persons with Disabilities (PNIPD) (Associação de Portadores de Esclerose Múltipla de Santa Maria e Região, 2021). The *Lírio* Civil Society Organization has 120 registered users with MS, and only eight of them are volunteers. Most of the *Lírio* Civil Society Organization 's users (70%) live in the municipality where it is located - Santa Maria, state of Rio Grande do Sul, and the remainder (30%) come from other municipalities and states. In 2020, the COVID-19 pandemic negatively affected the Civil Society Organization 's volunteer staff: six volunteers completely stopped participating in the Civil Society Organization and only two continued with their activities remotely. The reduction in the number of volunteers associated with the implications of the pandemic culminated in the partnership between the *Lírio* and *Dália* Civil Society Organizations.

The *Dália* civil society organization : comings and goings in the (re)construction of a collective path

With the encouragement and support of ABEM, in September 1992, a group of people diagnosed with MS created the state section of this association. However, in 1998, the ABEM state section, following ABEM's statutory guidelines, withdrew from the national association and changed its name to *Dália* (*Dália* Association of People with Multiple Sclerosis). Composed exclusively of people diagnosed with MS, the *Dália* Civil Society Organization interrupted its activities in 2016 because part of its volunteers developed physical limitations and increased symptoms of the disease. In 2019, a group of people with MS sought the help of the *Lírio* Civil Society Organization and ABEM to restructure the *Dália* Civil Society Organization and create a new Employer Identification Number (CNPJ). Since then, the *Lírio* and *Dália* Civil Society Organizations have worked in partnership developing information campaigns about MS and public policies to assist people with MS (Associação Gaúcha de Portadores de Esclerose Múltipla, 2021). It is worth noting that the lack of records on the paths of this joint entity, since its creation, hinders the detailing of these processes. Members of the *Dália* Civil Society Organization estimate that approximately 200 people with MS are users of the organization; however, only eight are volunteers. As in the *Lírio* Civil Society Organization , the *Dália* Civil Society Organization's volunteer staff was also negatively affected by the COVID-19 pandemic, and 10 of its volunteers completely stopped participating in the Civil Society Organization and only two continued with their activities remotely.

Facing the Barriers Imposed by the Pandemic: Bringing the Collectives Together

In compliance with municipal guidelines and decrees, in March 2020, the *Dália* and *Lírio* Civil Society Organizations suspended all planned collective and in-person activities. The entities are maintained with financial resources obtained through the development of socio-educational projects financed by private enterprises. When confronted with the COVID-19 pandemic, both entities sought strategies to continue the projects, as well as to maintain the budget necessary for their operation. With their doors closed and the need for social distancing of their volunteers (who are included in the risk group for COVID-19 because they have a chronic disease that acts directly on the immune system), the entities came together to rethink alternatives to their collective everyday life.

Through remote meetings, the volunteers shared goals and objectives common to both Civil Society Organizations. In these meetings, the collective expressed uncertainties and fears about the possible implications of the coronavirus on the health of people with MS. From questions about the need for special restrictive care, discontinuation of treatment with immunosuppressive medications, indication of vaccines, conduct to be followed in the event of suspension of outpatient care, among others, the need for union between the Civil Society Organizations became evident. According to Freire (1981, p. 57), when individuals recognize the identity of their interests as part of a dominated majority, and no longer as part of a divided minority, “they see each other as companions on a journey”. From this perspective, seeking to face the barriers imposed by the pandemic, the two Civil Society Organizations started the process of occupational reconstruction (Frank & Santos, 2020). By sharing their actions, the Civil Society Organizations engaged in collective activities to disseminate information about MS and the COVID-19 pandemic, as well as to organize events traditionally held in the ME Awareness Month, which is August (*Agosto Laranja*) in Brazil (Amigos Múltiplos pela Esclerose, 2022).

The virtual universe as a network of support, interaction and participation

After identifying the goals and desires of the collective with regard to facing the barriers imposed by the pandemic and bringing the two groups together, the methods and resources available to carry out the proposed activities began to be identified. Using virtual communication platforms to conduct the meetings, the Civil Society Organizations identified social media as an essential resource in their occupational reconstruction processes. In constant interaction through instant messaging and video calling applications, the volunteers defined the possibilities to perform the tasks and shared ideas and information about carrying out one or more activities. Virtual communication was recognized as a resource that facilitates interaction and social participation, capable of breaking the barriers imposed by social distancing.

Among the activities developed, we highlight the live streams held between May and December 2020. In May 2020, the “**Information is the best medicine**” campaign began, and was extended until December the same year, becoming the *Dália* Civil Society Organization’s central idea and purpose. In August 2020, the III State

Symposium on Multiple Sclerosis was held, with the theme "Multiple Sclerosis in times of Pandemic". Conceived by the *Lírio* Civil Society Organization , the symposium live streams occurred daily between August 24 and 30, 2020, and were disseminated by both Civil Society Organizations through Instagram, YouTube and Facebook, remaining available to the population on their respective websites. Professionals from different areas of knowledge who presented topics related to the diagnosis and treatment of MS participated in the live streams. Volunteers from organizations of people with MS from several Brazilian states participated in the live streams, debating the impacts of the pandemic on the Civil Society Organizations. The themes health and spirituality, work, and reorganization of everyday life were also addressed. People with MS, students and professionals from different areas of health and the social sciences participated in the 38 lives held in 2020, actively interacting in discussions through instant messages, expressing their questions and reflections.

Frequently asked questions about MS, its prognosis and possible treatment opportunities were mentioned by the participants, showing that access to information about the disease is a constant need, validating the efforts of the Civil Society Organizations to develop access to information campaigns. Problems such as unavailability of medication, questions about the production of vaccines against the coronavirus, risks of complications in the treatment of MS, interruption of outpatient care in health services and Civil Society Organizations, were also mentioned by the participants. To meet the demands of the participants, the *Dália* and *Lírio* Civil Society Organizations organized a support network formed by several Civil Society Organizations in the country, as well as by digital influencers, aiming to favor access to the information needed to solve problematic situations. Another relevant fact that deserves to be highlighted was the need for actions to welcome new users, since a considerable number of people were diagnosed with MS during the pandemic period, when the in-person activities of the Civil Society Organizations were suspended. This fact culminated in the creation, by the *Dália* Civil Society Organization , of the "*Correspondentes*" project, which proposes the reception of people with MS from a support network composed of people with MS from different regions of the country. The welcoming actions of this project occurred through instant messages and video calls, thus the information needs could be met while respecting the sanitary measures.

Distance care strategies are viable in the practice of occupational therapy and other health professions, and are supported by Resolution no. 516 issued by the Federal Council of Physiotherapy and Occupational Therapy (COFFITO) (Brasil, 2020) on 20 March 2020, which regulated teleconsultation, telemonitoring, and teleconsulting as possible work modalities aiming to allow the continuity of actions for some population groups assisted by occupational therapists. Muñoz (2020) highlights the need for occupational therapy to favor support networks during the COVID-19 social distancing period, and Malfitano et al. (2020) advocate these modalities of care, emphasizing the need for occupational therapists to consider the elements that permeate social inequality, exacerbated during the pandemic.

Another relevant aspect about the live streams and virtual communication resources available refers to their high potential to disseminate information. Except for productions with limited disclosure due to copyright, content posted in public domain could be shared at any time, anywhere, by anyone with Internet access.

Reflections on the Experience of the Occupational Reconstruction Process

The everyday lives of the Civil Society Organizations addressed in this experience report are marked, since their beginning, by the involvement of people with MS in collective occupations. The central purpose of these occupations is to raise the population's awareness of MS and its implications in the everyday lives of individuals affected by this disease. It is from the involvement of individuals in processes of continuous awareness of hegemonic dynamics and the recognition of dominant practices sustained in daily work that individuals and collectives acquire occupational awareness (Ramugondo, 2015). According to Ramugondo (2015), occupational awareness is characterized by the critical notion about everyday life, which allows the individual and the collective adequate understanding to promote potentially liberating actions. For the aforementioned author, occupational awareness acquired through critical reflection on everyday life offers individuals and collectives conditions to interrupt cycles of oppression and inequality. In this perspective, Freire (1981) anticipated that individuals become aware of themselves and others through permanent mobilization and active participation in a political practice that defends their interests. Both Civil Society Organizations were composed of individuals who collectively mobilized to break excluding dynamics that limit the basic rights of access to health and social participation of people with MS. Thus, we extrapolate from the thinking of Ramugondo & Kronenberg (2015) to affirm that, based on the intentionality of collective occupation aimed at the search of social rights and the appreciation of life, the Civil Society Organizations created conditions that favored the occupational awareness of their members. Therefore, by engaging in occupations that were meaningful to them, the members of these entities acted to implement the necessary changes so that people with MS can live in a fairer society.

The COVID-19 pandemic did not prevent Civil Society Organization participants – inspired by their occupational awareness and strengthened by their sense of collective belonging – from overcoming imposed adversities and reconstructing their collective occupations. For the people involved in these Civil Society Organizations, breaking through the barriers of social distancing was not limited to figuring out how to use virtual platforms. It was necessary to unite the potentialities of the collective to overcome shyness and lack of experience with the available technological resources (personal aspects) (Borges & Jambeiro, 2016). According to Ramugondo & Kronenberg (2015, p. 12), the process experienced by Civil Society Organizations is a natural phenomenon, since humanity is "constantly being shaped by what we **are able or unable** to do within groups, communities, and society".

In this study, we present the actions of the individuals and the collective who, based on critical reflections on the collective everyday life that unites them, imagined and created new possibilities about everyday doing. Focusing on actions to raise awareness of MS and considering their abilities and skills, individuals were freely and spontaneously reorganizing functions and activities, ensuring their engagement in the actions proposed by the collective. According to Rudman (2013), freely chosen and imagined occupation creates new possibilities for social engagement. We understand, therefore, that the collective construction of Awareness Campaigns, such as those presented in this experience report, can be characterized as a strategy for occupational reconstruction (Frank & Santos, 2020). We understand that it is through the sharing of concrete conditions of existence and intentionality that the individual and the collective gain visibility to change reality. According to Palácios (2015), it is from the everyday actions and omissions experienced in the relationship with others that collective occupations develop new ways of life. For the aforementioned author, occupation is a social construction that arises from the collective expression of culture, history, and economic and material aspects, evidenced in the ways of doing and living everyday life. Kantartzis & Molineux (2017) reflect that the collective occupation developed in Civil Society Organizations is more than the simple gathering of people to debate or protest, but a support that helps organize the public world. They add that the importance of collective occupation in these spaces goes beyond cooperation and division of responsibilities between individuals, and also assists in structuring and creating social standards.

As participants and observers of the phenomena and processes described in this experience report, we emphasize the extensive work of the members of these entities, who were always guided by the guarantee that the occupations developed were freely chosen by individuals, always aiming at collective results.

Final Remarks

The Civil Society Organizations addressed in this experience report are collective spaces that advocate for people with MS and are dedicated to occupations aimed at awareness campaigns about this disease, as well as to the full social inclusion of these people. Included in the risk group of individuals with chronic diseases, people with MS who use immunosuppressive medication need greater attention for care related to the prevention of COVID-19, given that these drugs decrease the body's immune response. However, studies have shown that the medicines used by the vast majority MS patients fortunately act as protectors of the immune system, which ended up offering these people some tranquility to continue only with the necessary and common care for the general population. Thus, it was found that the greatest impact of the COVID-19 pandemic on the everyday lives of MS patients and their families was related to the need for social distancing, suspension of laboratory and non-urgent consultations, delays in receiving medications, and suspension of support groups and integrative practices offered by Civil Society Organizations, in addition to the obvious difficulties that affected society as a whole.

For the volunteers of the Civil Society Organizations studied, social distancing negatively affected the management of their entities, once the interruption of collective and shared actions resulted in extreme fragility in the execution of the entities' tasks. At the same time, the use of social media devices emerged as an easily adaptable resource with great potential to be explored in actions in which the physical presence of participants was not necessary. Some limitations are worth mentioning, such as instability of the Internet signal, people with little mastery in the use of the platforms, external interference that diverted the attention of participants during the events, among others. Thus, we understand that it is valid to suggest that, for the use of these tools, it is necessary that these occurrences be foreseen to avoid situations that may negatively influence the proposed activities. For the members of the Civil Society Organizations addressed in this study, virtual platforms constituted a powerful resource, creating a "virtual space" that enabled the reconstruction of collective occupations traditionally carried out in person, from a new configuration of doing together, even being geographically apart. Nevertheless, it should be noted that, although the creation of a virtual space has minimized the impacts of the interruption of in-person collective and shared actions in these entities, most of their volunteers did not adhere to this proposal. We consider that there may be many reasons for the non-participation of all, and understand that this fact highlights the need for research that provides adequate subsidies so that we can understand more comprehensively the processes of occupational reconstruction, such as those described in this study.

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Author’s Contributions

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