

Experience Report

# Occupational therapy intervention with a young male adult living with HIV/AIDS and COVID-19: a case study<sup>1</sup>

## *Intervenção da terapia ocupacional com um jovem com HIV/AIDS e COVID-19: estudo de caso*

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### Abstract

**Introduction:** People living with HIV/AIDS may experience restrictions in daily activities because of the disease and its treatment. During the COVID-19 pandemic, these difficulties became more pronounced. Additionally, these individuals have specific needs for palliative care that are often overlooked. **Objective:** To report the case of a young adult with HIV/AIDS who was hospitalized with COVID-19, focusing on the occupational therapy intervention process grounded in the principles of palliative care. **Methods:** A case study conducted following the CARE Statement and Checklist. **Results:** The patient was hospitalized with COVID-19 and assessed using the Functional Independence Measure (FIM), Identification of Palliative Needs (NECPAL), and Palliative Performance Scale (PPS) instruments. He exhibited total dependence in activities of daily living (ADL) and emotional distress related to fear of death, along with low adherence to treatment. His clinical history included multiple complications qualifying him for palliative care. Occupational therapy interventions included training on ADL and motor skills, environmental adaptations, active listening, strengthening health self-management, and guidance on advance care planning. The patient regained independence, improved treatment adherence, and resumed life projects. **Conclusion:** The findings highlighted the grief associated with dependence on activities and the isolation due to COVID-19, the importance of timely occupational

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therapy follow-up, the role of health self-management, and the need for a thorough assessment of ADL for rehabilitation, including in palliative care contexts.

**Keywords:** Occupational Therapy Department, Hospital, Activities of Daily Living, COVID-19, HIV, Palliative Care.

### **Resumo**

**Introdução:** Pessoas vivendo com HIV/AIDS podem apresentar restrições em atividades cotidianas como consequência da doença e do tratamento. Durante a pandemia de COVID-19, tais dificuldades se avultaram. Além disso, essas pessoas possuem necessidades específicas em cuidados paliativos que, por vezes, são negligenciadas. **Objetivo:** Relatar o caso de um jovem com HIV/AIDS, hospitalizado com COVID-19, a partir do processo de intervenção de terapia ocupacional, fundamentado nos princípios dos Cuidados Paliativos. **Método:** Estudo de caso elaborado segundo o *CARE Statement and Checklist*. **Resultados:** O paciente foi hospitalizado com COVID-19 e avaliado por meio dos instrumentos Medida de Independência Funcional (MIF), Instrumento para Identificação de Necessidades Paliativas (NECPAL) e *Palliative Performance Scale* (PPS). Apresentava dependência total nas atividades de vida diária (AVD) e sofrimento emocional relacionado ao medo da morte, além de baixa adesão ao tratamento. Sua história clínica incluía diversas complicações que o elegiam para os cuidados paliativos. As intervenções de terapia ocupacional incluíram: treino das AVD e habilidades motoras, adequação ambiental, escuta, fortalecimento do autogerenciamento da saúde e orientações sobre diretivas antecipadas de vontade. O paciente recuperou a independência, melhorou sua adesão ao tratamento e retomou projetos de vida. **Conclusão:** Destacaram-se o luto pela dependência nas atividades e pelo isolamento decorrente da COVID-19, a relevância do acompanhamento de terapia ocupacional em momento oportuno, a atuação no autogerenciamento da saúde e a necessidade de avaliação minuciosa das AVD para a reabilitação, inclusive no contexto dos cuidados paliativos.

**Palavras-chave:** Serviço Hospitalar de Terapia Ocupacional, Atividades Cotidianas, COVID-19, HIV, Cuidados Paliativos.

## **Introduction**

People living with the human immunodeficiency virus (PLHIV) may develop acquired immunodeficiency syndrome (AIDS) and experience episodic or permanent impairments due to metabolic, cognitive, and physical limitations (Banda et al., 2019; O'Brien et al., 2020). In Brazil, in 2021, an estimated total of 960,000 PLHIV was reported, with 76% receiving follow-up care from health services. Between 2010 and 2019, 37.6% of HIV-related hospitalizations occurred in the Southeast region, with 51.35% taking place in public hospitals, lasting an average of 19 days (Santos et al., 2020).

During the COVID-19 pandemic, the mortality risk from the disease was estimated to be twice as high among PLHIV (Bhaskaran et al., 2021). A review mapped the clinical course of COVID-19 co-infection in this population. The main complications identified included hypoxemia, pneumonia, leukopenia, and cardiopulmonary arrest (Schaurich et al., 2021). The Ministry of Health, through the Department of Chronic Conditions and

Sexually Transmitted Infections (DCCI), indicated that between 2020 and 2021, there was a 20% reduction in the number of PLHIV initiating antiretroviral therapy (ART), associated with difficulties in diagnosis during the pandemic (Brasil, 2022).

Given this complexity and the experience of living with a diagnosis that may threaten life expectancy, PLHIV may be eligible for palliative care (PC) (Ahmad et al., 2024). PC is a holistic approach to care aimed at individuals experiencing suffering related to severe illness, with the goal of improving the quality of life of both the patient and their family. A severe illness is defined as a condition with a high risk of mortality that affects functionality and/or results in a burden of symptoms, intensive treatment, and caregiver stress (Radbruch et al., 2020).

In 2020, 22.2% of PC needs were reported by adult PLHIV (Worldwide Palliative Care Alliance, 2020). Additionally, these individuals experience symptoms such as chronic pain, which affect medication adherence, mobility, and overall quality of life (Povshedna et al., 2023). Thus, PC should be provided to establish care preferences, manage symptoms, and support PLHIV, particularly when recovery is unpredictable or complicated (Ahmad et al., 2024).

Occupational therapists are part of PC teams and facilitate participation, independence, and autonomy in everyday life by applying their expertise in the relationship between the individual, activity, and context (American Occupational Therapy Association, 2020). These professionals identify restrictions in the occupational roles of PLHIV during hospitalization and implement actions to restore these roles (Rocha & Ruzzi-Pereira, 2022). Occupational roles refer to socially expected behaviors within an individual's community that affirm their identity and contribute to structuring their daily routine (American Occupational Therapy Association, 2020). Examples of roles affected in PLHIV include those of worker, student, and religious community member (Rocha & Ruzzi-Pereira, 2022).

One of the exclusive responsibilities of occupational therapy (OT) is training in Activities of Daily Living (ADLs), which involves skill development across motor, sensory, perceptual-cognitive, mental, emotional, behavioral, functional, cultural, social, and economic domains, either in real or simulated activity contexts. Moreover, OT enables ADLs through adaptations of steps and environments or by restoring specific functions (Nascimento et al., 2023).

Recently, interventions described in PC and with PLHIV have included non-pharmacological symptom management, adaptations of basic and instrumental activities of daily living (Tavemark et al., 2019), facilitation of access to healthcare services (Agner & Barile, 2020), and social inclusion (Nhunzvi et al., 2020).

The dissemination of rehabilitation actions for PLHIV has been highlighted as a research need—especially to identify facilitators and barriers to treatment (O'Brien et al., 2020)—which this study aims to address. Additionally, despite its potential, OT remains underutilized in PC, and its role is still not fully recognized within PC teams (Knecht-Sabres et al., 2019).

Based on these considerations, this study aimed to report on the case of a young male adult living with HIV/AIDS, hospitalized with COVID-19, through the lens of the OT intervention process.

## **Method**

This is a case study conducted following the CARE Statement and Checklist in the infectious and parasitic diseases (IPD) ward of a university hospital in southeastern Brazil between May and October 2020.

The follow-up began when occupational therapists were integrated into the hospital's frontline COVID-19 response team. Patients with COVID-19 were admitted to either the intensive care unit (ICU) or the IPD ward, depending on the severity of their condition. In the ward, occupational therapists assessed patients to determine the need for follow-up care without requiring a referral from another team member. The team included nurses, physicians, nutritionists, psychologists, physical therapists, speech-language pathologists, and social workers. The workflow process was previously described (Nascimento et al., 2023).

The case was selected because of its complexity and the positive result on the NECPAL-BR prognostic tool for identification of palliative needs (Santana et al., 2020). This instrument includes the surprise question: "Would you be surprised if this patient died over the next year?" as well as biopsychosocial indicators such as functional decline, delirium, emotional distress, social vulnerability, and other condition-specific indicators, including those for HIV. All items have dichotomous responses (yes/no). A NECPAL result is considered positive when the answer to the surprise question is "I would not be surprised," combined with the presence of one or more indicators (Santana et al., 2020).

The intervention process, based on a review of the medical records and reports, was discussed by the team. Following this stage, information was extracted to construct the case, and assessments were analyzed considering recent literature. The assessments included the Functional Independence Measure (FIM) and the Palliative Performance Scale (PPS). The FIM consists of 18 items divided into two categories: motor (FIM-m) and cognitive (FIM-c), scored from 1 to 7, where 1 indicates "total assistance" and 7 indicates "independence" (D'Andrea et al., 2020). The PPS assesses functionality in relation to disease progression and comprises five domains: ambulation, activity and evidence of disease, self-care, intake, and level of consciousness, with results ranging from 0% to 100% (Fiorentino et al., 2020).

These instruments were administered by occupational therapists at hospital admission, discharge, and three weeks after discharge. Clinical data, including information on OT interventions and patient statements, were extracted from electronic medical records. The FIM-m scores were organized into a graph, while the description of performance in ADLs and the team's impressions were recorded in a report.

This study was approved by a Research Ethics Committee for Human Subjects under No. 4.240.785.

## **Results**

### **Patient history**

Arthur (fictitious name) is a 27-year-old, white, Christian, single man. He worked at a bus station but became unemployed before hospitalization and began receiving social security benefits. He completed high school and aspired to become a history teacher. His HIV infection resulted from vertical transmission. During childhood, his

grandmother managed his treatment; however, during adolescence, he exhibited irregular adherence. At that time, he also began abusing cocaine. In early 2020, he voluntarily admitted himself to a rehabilitation clinic for three months. Since 2009, he has undergone 30 hospitalizations, totaling 593 days.

Arthur had always been independent in his activities. His interests include listening to music, watching movies, and using the Internet. He considers himself outgoing and enjoys having friends. He had a few romantic relationships but, during the hospitalization described, did not believe maintaining a long-term relationship was possible because of his HIV status.

## **Clinical history**

Arthur has HIV, idiopathic thrombocytopenic purpura, multiple treated infections, and hypertension. In 2017, he suffered a cerebrovascular accident (CVA) with left-side hemiparesis and developed osteomyelitis, leading to the amputation of his left hallux. After physical therapy sessions in 2017, he retained no major sequelae from the CVA, except for impaired gait due to foot drop, and used a cane. He was independent in all activities.

In May 2020, he was admitted to the emergency department in a wheelchair, presenting with weight loss, dyspnea, disorientation, dysarthria, odynophagia, severe metabolic acidosis, and respiratory alkalosis. Since his hospitalization in November 2019, he had not adhered to ART. At the time of admission in 2020, his viral load was 198,307 copies/mm<sup>3</sup>, and his CD4 count was 26 cells/mm<sup>3</sup>. He was diagnosed with disseminated tuberculosis, COVID-19, and pneumothorax, requiring a chest drain and oxygen supplementation. He developed delirium but, despite COVID-19, did not experience other respiratory symptoms after pneumothorax resolution and was able to breathe ambient air again. At the beginning of hospitalization, he was placed in respiratory isolation and was followed by a multidisciplinary team.

## **Assessment**

Arthur was considered eligible for PC based on a positive NECPAL result. The response to the surprise question was affirmative, with the following parameters: weight loss >10%, a reduction of more than 30% on the PPS, severe dependence (PPS <50), malaise, emotional distress, social vulnerability, more than two urgent admissions in six months, and AIDS (Santana et al., 2020).

An analysis of his occupational profile and performance was conducted (American Occupational Therapy Association, 2020). On the FIM, he scored 56 overall, with 21 in the FIM-m and 35 in the FIM-c. He required assistance with all ADLs but had no cognitive impairment.

His PPS score was 30%. He was bedridden, did not engage in any activities, had extensive disease, was completely dependent for self-care, had normal intake, and maintained full consciousness. Regarding motor skills, limitations were observed in reaching, lateral trunk inclination, coordination, object manipulation, and endurance, though fine motor skills and dexterity were preserved. Muscle function assessments revealed weakness in elbow, shoulder, and knee flexion, as well as in the hip and trunk. No deficits were identified in processing skills or social interaction abilities.

Arthur was deeply saddened by his illness and hospitalization, expressing fear of “what will happen after death” and of “being thrown into the lake of fire” (extracted from medical

records). He felt “regretful” about his irregular adherence to ART and suffered from the isolation imposed by COVID-19, as he was unable to communicate with his family.

### **Occupational therapy diagnosis**

“Dependent in ADLs. Displays limitations in motor performance skills, decreased volition to engage in occupations, and impoverished everyday life. Previously, he performed activities independently and is thus experiencing grief due to the intense disruption of his routine and occupational roles. The need for total assistance in ADLs causes suffering for Arthur, especially because he relies on others for personal hygiene. He is extremely distressed by multiple life-threatening diagnoses” (extracted from medical records).

### **Objectives**

The intervention aimed to promote independence in ADLs, mitigate the detrimental effects of hospitalization (immobility, emotional distress, and reduced engagement in daily activities), and strengthen self-management of health.

### **Intervention process**

The therapeutic relationship was initiated by identifying the patient’s routine, occupational roles, and interests, as well as engaging in active listening regarding his fear of death. Arthur was then encouraged to participate in activities such as listening to his favorite music and reconnecting with his spirituality. To facilitate communication during isolation, arrangements were made for him to receive his mobile phone, following an agreement with the multidisciplinary team.

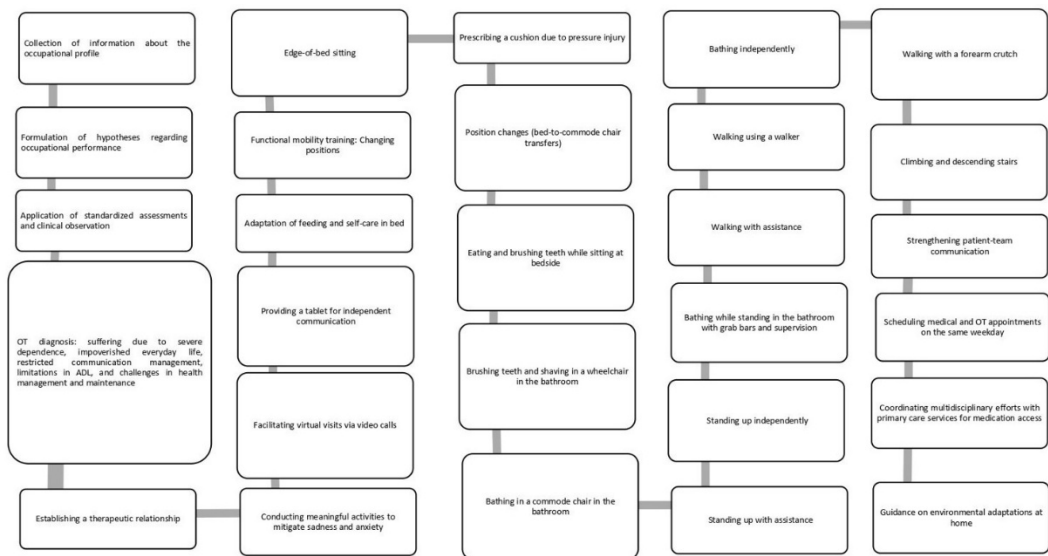
Concerning performance in ADL, the following strategies were implemented: 1. Adaptation – reducing activity demands to enable engagement; 2. Gradation: gradually decreasing the level of external assistance as the patient acquired skills; Training – promoting the development of performance skills during activities, as shown in Figure 1.

### **Facilitation of performance on ADL**

The hospital room environment was adapted so that Arthur could eat independently by bringing the table closer to the bed and removing food packaging. The activity of brushing his teeth was adapted to be performed in bed.

Before training sessions on ADL, blood pressure, heart and respiratory rate, and peripheral oxygen saturation (SpO<sub>2</sub>) were measured, and arterial blood gas analysis was checked when available. These assessments were necessary because of silent hypoxemia described in COVID-19, where SpO<sub>2</sub> decreases without dyspnea (Tobin et al., 2020). Laboratory tests were reviewed daily, particularly because of the thrombocytopenia and anemia related to purpura, which contraindicated mobilization and getting out of bed.

Functional mobility training began with transitioning from a supine position to sitting at the edge of the bed. Within a week, Arthur developed the endurance needed to maintain a seated position during meals and while brushing his teeth. However, because of weight loss and prolonged bed rest, he developed a pressure injury in the sacral region, causing pain. A cushioned and easily cleanable seat was prescribed for his chair to enable him to perform these activities.



**Figure 1.** Flowchart of occupational therapy interventions. Source: Prepared by the authors, 2024.  
Caption: \*TO – occupational therapy. \*\*ADL – activities of daily living.

Training continued for standing up from bed and performing personal hygiene. After six weeks, Arthur was able to transfer from the bed to a wheelchair and from the wheelchair to the toilet, requiring only supervision because of the risk of falling. Simultaneously, training began for intimate hygiene and showering while seated.

By the second month of intervention, Arthur was walking short distances (<15 m) using a walker and was able to shower in a standing position using support bars. However, foot drop in his left foot made activities more difficult. To address this, a Harris-type splint was made to facilitate walking. Functional mobility training continued but was still challenging because of balance and endurance difficulties.

During this period, Arthur’s clinical condition worsened, with thrombocytopenia and lymphopenia. As a result, ADL training outside the bed was suspended. This decision caused him distress, as he expressed frustration over the prolonged hospitalization and communication gaps regarding his clinical condition. OT interventions then focused on maintaining his abilities, providing emotional support, engaging in activities of interest, and improving his communication with the medical team.

During one session, Arthur expressed a desire to discuss serious diagnoses like his own and his preferences regarding end-of-life care. The occupational therapists identified priorities related to advance care planning and included them in his medical record. Among these priorities, he emphasized his wish to maintain as much independence as possible in his activities until the last moment.

**Discharge plan**

As discharge approached, functional mobility training continued, replacing the walker with a forearm crutch. Training included climbing and descending stairs, as Arthur lived in a two-story house. Non-slip material was provided for the bathroom floor, and both he and his family members received guidance on fall prevention.

During this period, Arthur was informed that he would need to return to the hospital twice a week for filgrastim administration to treat neutropenia. The difficulty of accessing the hospital this often worried him because of financial constraints and mobility issues related to public transportation. Filgrastim is a high-cost medication, making it unaffordable for the patient without support from the Unified Health System (SUS).

To address this, the occupational therapists, in collaboration with the medical team and social services, arranged for the medication to be sent to the Family Health Unit (USF) in his region, which took responsibility for administering filgrastim. Additionally, Arthur was referred for follow-up at the OT outpatient clinic on a biweekly basis.

Intervention outcomes

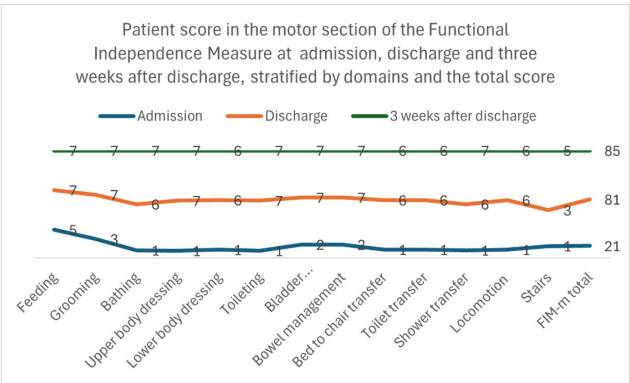
A total of 36 therapy sessions were conducted. The patient achieved independence in the domains of eating, personal hygiene, dressing the upper body, toilet use, and sphincter control. In the domains of bathing, dressing the lower body, transfers, and walking, he achieved modified independence, meaning these activities required adaptations, orthoses, extended time, or support for safety. In the stairs domain, he progressed from total dependence to performing the activity with moderate assistance, requiring help for balance and safety.

Arthur reached 80% on the PPS, indicating full ambulation, some evidence of disease, full self-care, normal intake, and full consciousness. Qualitative outcomes included increased volition in planning post-hospitalization life projects, such as returning to work and studying, as well as greater engagement in health management activities, demonstrated by his concern about treatment adherence and the initial steps in formulating his advance care planning.

Follow-up

Three weeks after discharge, Arthur was evaluated at the OT outpatient clinic, scoring 100% on the PPS.

As for the FIM, the domains of dressing the lower body, bed-to-chair transfer, toilet transfer, and walking remained unchanged, suggesting the need for continued follow-up. In the stairs domain, performance improved, possibly due to home practice, which provided training opportunities. The results are shown in Figure 2.



**Figure 2.** Patient’s scores in the motor section of the Functional Independence Measure at hospital admission, discharge, and three weeks after discharge, organized by domain and total score. Source: Prepared by the authors, 2024. Caption: FIM-m – motor section of the Functional Independence Measure.



Arthur continued treatment for tuberculosis and neutropenia at the USF. To enhance participation in activities, he remained in OT outpatient care after the follow-up evaluation. In the second half of 2021, he began his undergraduate studies in History, fulfilling one of his life projects, and was consistently adhering to his treatment up to the completion of this study.

## **Discussion**

There is a scarcity of studies addressing PLHIV as candidates for palliative care, despite the significant suffering associated with the diagnosis and treatment (Spencer et al., 2019). In this case, grief over dependence and the disruption of daily routines was particularly evident. Grief is understood as the distress arising from the perception of losing something essential to an individual's life, whether a person, an object, a way of living, or their own health (Prigerson et al., 2021). Increased dependence has been associated with prolonged and complicated grief (Nielsen et al., 2020).

Although the patient did not develop respiratory sequelae from COVID-19, he may have experienced psychosocial distress related to the disease, which can negatively impact performance in ADL (Stevens et al., 2019). Moreover, hospitalization itself can elicit profound existential fears, such as the fear of death, particularly among young individuals (Oliveira et al., 2023).

Involving PLHIV and their families in PC decision-making is crucial, especially given the challenges in integrating this approach within the continuum of care (Okoli et al., 2021). In this case, efforts were made, in collaboration with the healthcare team, to actively involve the patient in discussions about his treatment and to encourage responsibility for managing his health. Additionally, discussions progressed to explore care preferences in the event of symptom exacerbation.

Initially, self-care emerged as a source of distress and guilt for the patient. However, throughout the therapeutic process, it evolved into a means of reinforcing autonomy as treatment goals were progressively achieved. A key therapeutic intervention was the provision of emotional support, understood as "creating spaces for listening that enable demands [...] to be received, understood, and directed toward resolution" (Aniceto & Bombarda, 2020, p. 654). This underscores the broader role of OT in hospital settings, which extends beyond functional recovery to fostering engagement in personally meaningful life projects.

The timely initiation of OT in PC is essential to enabling participation in daily activities, even in cases where physical or cognitive function recovery is temporarily or permanently unfeasible. In this case, ADL training with adaptations was implemented during the patient's period of clinical decline, highlighting the importance of integrating OT at all stages of treatment.

The establishment of precise and individualized therapeutic goals is also fundamental. Although the PPS is widely used in PC practice, it does not appear to be sufficient for OT assessments, as occupational therapists require tools that provide detailed insights into activity participation and facilitate the development of individualized treatment plans. This case emphasizes the relevance of the FIM, which is particularly sensitive to changes in ADL performance over time.

Occupational therapy plays a critical role in facilitating early hospital discharge, as described by Lopes et al. (2020). In this case, OT interventions included promoting independence in daily activities, supporting adherence to treatment, and ensuring post-discharge follow-up. These measures are crucial in preventing rehospitalization and reducing associated healthcare costs, which were particularly high in Arthur's case.

This study has some limitations, including a nearly one-month delay between the patient's hospital admission and the initiation of occupational therapy, which may have contributed to the severe functional decline observed. Additionally, the frequency of therapy sessions—approximately three times per week—was constrained by the limited number of available professionals. It is also worth highlighting that the results reflect the collective efforts of the entire healthcare team rather than OT alone, as ADL dependence is a multifactorial condition (Wang et al., 2020).

To the best of our knowledge, this is the first study to provide a detailed account of OT interventions in PC for a patient living with HIV/AIDS during the COVID-19 pandemic. Despite the adversities posed by illness and hospitalization, the patient showed improvements in independence for ADL. Furthermore, he resumed his occupational roles and actively engaged in managing his health, ultimately preventing further hospitalizations.

The findings of this study contribute to the broader discussion on rehabilitation strategies for PLHIV, particularly within the Brazilian SUS, and offer a detailed account of OT interventions in this context.

Finally, the discussion on the eligibility of this population for PC is particularly relevant in the context of the COVID-19 pandemic, which has prompted broader societal reflections on life and death, especially among individuals with chronic illnesses.

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### Authors' contributions

Ana Paula Correa Ferreira: study design, organization of sources and/or analyses, application of the intervention, writing of the manuscript. Thamires de Matos Ribeiro: organization of sources and application of the intervention. Thainá Rodrigues de Melo: organization of sources, application of the intervention, and revision of the manuscript. Silvana Maria Aquino da Silva: revision of the manuscript. Janafina Santos Nascimento: writing and revision of the manuscript. All authors approved the final version of the text.

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