

The meanings of living from the perspective of Psychosocial Care Centers' users: life experimentations in Santos, São Paulo, Brazil

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Abstract *This research highlights housing as one of the dimensions of the lives of individuals who experience severe psychological suffering, which reverberates in their care and unique therapeutic plan. This paper aims to grasp the Psychosocial Care Centers (CAPS) users' meanings of their experiences of living in Santos (SP), Brazil. This qualitative research was conducted with users of different services through semi-structured interviews submitted to the thematic content analysis. This study identified how the conception of housing relates to protection, individuality, and affective memories that corroborate the construction of an expanded concrete life regarding living in freedom in the city, presenting plural housing located in different territories. Taking ownership of spaces reveals the possibilities and challenges inherent to social exchanges and daily experiences. Being and living in a house means having access to material and subjective goods, besides assuring care in freedom. However, there are still limitations in the effective exercise of social participation.*

Key words *Mental health, Housing, House, Personal autonomy*

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Introduction

The Brazilian Psychiatric Reform process and the consequent creation of a vast network of mental health care require knowing and elucidating how people with intense psychological distress organize themselves around housing when leaving guardianship imposed by total institutions. The compass of planning the National Mental Health Policy builds on the principles of the Italian deinstitutionalization by redirecting the hospital-centered model to a broad and complex design of a network of community services, seeking to build adequate conditions to live in freedom and, thus, consolidate a care plan that would transcend de-hospitalizing people who were living in psychiatric hospitals¹.

Deinstitutionalization characterized a practical work of transformation that begins within the asylums, as it proposes to change how people were “treated” (or not treated), now based on a complex set of actions that permeated the social body. The object of care started to deal with existence, and deinstitutionalization was based not on productive life but on the production of life, meaning, sociability, and the use of social and interactive spaces, which led to a gradual dismantling of asylums².

Among the concrete conditions to break with the asylum spaces and promote the guarantee of life in the city, the Therapeutic Residential Services (SRT) were created for long-term inmates in psychiatric hospitals with weakened or interrupted family and community ties³. A psychosocial rehabilitation financial aid was also established for those discharged from hospitalizations, called the *Volta para Casa* (Going Home) Program (PVC)⁴. Both underlie the deinstitutionalization strategies that underpin the Psychosocial Care Network (RAPS). While mental health policy has sought to make life in freedom effective in the Brazilian deinstitutionalization process, many challenges persist⁵, and the demand for housing seems to be one of the significant challenges of urban life.

Housing is a fundamental element for sustaining people’s physical and mental well-being with intense psychological distress, enabling the resumption of citizenship rights and integrating living in freedom. At first glance, a house can be considered as a rigidly geometric and spatial element. On the other hand, it is a receptive space providing comfort, which can condense and defend intimacy⁶. Indeed, these spaces forge the experiences of daily scenes, life stories, and the

effects of exchange and social values, such as affections, money, and powers⁷.

The idea of home is related to complex and concrete experiences of recognizing time and space use with domestic and affective rhythms, from the use of objects and opportunities in daily life, centered on the particularity of each individual, as with the different residents of a house⁸. A space for appropriation, housing is one of the main elements in the inclusion, integration, and maintenance of people with intense psychological distress in the social environment⁸.

By considering the home as a space for legitimizing affective and interpersonal relationships, exchanges, and everyday contractuality, we also revive the subjective dimension of living and belonging to a space called “your own”. From the perspective of protection, an integrative space, and recollection, it seems relevant that CAPS users elucidate the experience of living in a house from the process of care in freedom and psychosocial care actions. Thus, this study aimed to apprehend the meanings of the experiences of living for people who endure intense psychological distress and are monitored at the Psychosocial Care Centers in Santos (SP), Brazil.

Methods

This study selected qualitative research to explore the social reality and the dynamic individual and collective life of subjects, considering the richness of their existence’s meanings⁹. Data was collected through semi-structured interviews following a dialogic meeting based on guiding items. Respecting the interest in talking about the topic and availability, all signed the Informed Consent Term voluntarily with anonymity assured by fictitious names. The Human Research Ethics Committee of the Federal University of São Paulo approved the study under Opinion N° 2.777.375.

The participants were ten people with follow-up in CAPS modality III, located in different city regions. We chose to approach two users in each of the services to elucidate realities in different territories. Five participants have a long-term hospitalization history, and five did not go through psychiatric hospitals with care maintenance at the CAPS, even in moments of more significant psychological destabilization. We interviewed five females and five males, aged between 39 and 65 years. Four men self-identified as black, while five women and one man self-declared white. Four respondents had incomplete

elementary school, one had completed elementary school, two had completed high school, one had not completed higher education, one had completed higher education, and only one was illiterate. Two did not have a fixed income and had family support, while the others were retired or received some benefit – Continuous Cash Benefit (BPC) or the PVC Program.

The interviews were digitally recorded, transcribed, and subjected to thematic content analysis, operationalized in three stages: Pre-analysis, material exploration, and treatment of the findings obtained with interpretation in dialogue with the narrative review of studies on the topic⁹. Three recurrent themes were listed to analyze housing design, ways of living, and relationships with space and territory. The first theme aimed to apprehend the meaning of home from its relevance, memories, and perspectives. The second elucidates the home in its territorial, social, and economic possibilities and limitations. The third theme identifies how users take ownership of their homes.

Results and discussion

Santos has a critical historical role in the Brazilian Psychiatric Reform and is one of the pioneers promoting effective Mental Health care transformations, starting from the intervention in the former *Casa de Saúde Anchieta* in May 1989. The transformations promoted by deinstitutionalization triggered the configuration of community services inspired by the Italian democratic psychiatry, implementing a psychosocial care network consisting of open and regionalized services¹⁰. The Psychosocial Care Network currently comprises 34 PHC units; five adult CAPS modality III; one CAPS Alcohol-drugs modality III; one CAPS Alcohol-Drugs for Children and Adolescents, modality III; three Children's CAPS; three Therapeutic Residential Services; one Psychosocial Rehabilitation Section; three Emergency Care Units; one Street Clinic team; and the Mobile Emergency Care Service (SAMU).

Participants live close to the CAPS in different city areas, whether in isolated houses, rooms in collective housing, or popular apartments. The houses are located in an urban area of a coastal city with high social inequality, which increases the housing challenges of a tourist city on the south coast of São Paulo with a high living cost. One can walk around the garden on the organized beachfront and come across poor houses

on the hills just a few blocks away. The historic commercial houses were transformed into sizeable collective housing in the central region, with a sublet of rooms, also known as tenements. The city is home to a vast peripheral region with stilts built over the mangrove swamp.

The concept of home

Home concepts refer to a powerful space for exchange, the construction of bonds, and human relationships. Primarily, they differentiate the home as a physical structure, while a house is where they carry out the act of living and doing small household chores. Thus, unlike being, residing leads to a dynamic view in the use of the home or dwelling, considering time and space based on relationships established materially and subjectively in the intimate game between being and residing¹¹. They can be considered ways of presenting human beings' intrinsic need for shelter⁸ and space for carrying out significant activities in their cultural, social, environmental, and temporal particularities, which is daily life in a particular world.

Regarding the imaginary of protection and shelter brought with the notion of housing, Tugny analyzes the place called home as the first shelter, and an attempt at the protection that takes place in Adam's imagination when he was expelled from paradise with his hands crossed over the face in a defensive gesture to face the rain⁸. This precarious situation allowed a reflection on the human weaknesses and needs in its original nudity in the face of the shelter and protection elements brought about by the home. From this perspective, home can be understood as a functional space in a necessary response to the conditions and aggressions of the world and sustains a symbolic place of personal protection. This idea of protection appears in some statements:

Nobody will catch you inside the house. Nobody will hurt you. We have more security. (Ivan)

It is our home, a place where we welcome each other. Because there are many people on the street, right? There's nothing to eat... it's crucial to have a place. (Alvaro)

Housing is everything, right? You shelter from the streets, cold, and violence. (Fausto)

Faced with the experience of intense psychological distress and in their life stories, their wishes and statements were often invalidated¹². The feeling of inhabiting was invalidated with the non-legitimization of their experiences in protective spaces. We can also identify that the home

refers to a genuine and concrete sensation of protection since it unanimously appears as a space of security, retreat, where one can protect from the outside world and receive individualities.

If the home encompasses a functional space that protects the conditions imposed by the world, it must respond to people's needs so that it can withstand and traverse moments of crisis and psychic instabilities. Thus, if the "ideal" home emerges as a protection system, it also has crevices, insofar as fear, anxiety, and insecurity are also experienced in it. The intimate relationship between the inhabitant and the home makes the impressions of the house change over time and the events it raises or embraces⁸. The lines below illustrate memories of previous houses.

[...] I was raised in the countryside, with my grandparents... We didn't have the conditions there. [...] I was someone who was beaten a lot, got punched in the nose, and my nose bled. My mom thinks I don't like her. However, whatever happened, I became distraught because my grandmother told me that I was abandoned. Then, I started going out on the streets since I was little. (Henrique)

Many memories... The strongest one is the house in São Paulo in the 1960s with my parents, in the heart of SP, SP downtown, the Bexiga neighborhood... it's kind of magical, right? Because it's a time that will never come back, [...] that I miss. And Santos, too, right? When I lived with quality of life, closer to the sea. (Gabriela)

It can be said that a house is a space integrating experiences, memories, and affectations that corroborate our individual and social construction. Living implies physical and subjective space. The respondents' reports show that the house refers to memories of food, lived environments, emotional ties, family relationships with mother, father, childhood, and life fragilities, very restricted social and financial conditions. In many aspects of the inhabited space and the range of experiences that accompany it, home is a supportive place to build one's life, as it also indicates a possible exercise of citizenship, as valued by Fausto:

Living in a place is having your address, being a person recognized by society. As bad as the place can be, you're a person. You can have an account, everything... if someone doesn't have an address, he can't have an account or anything! I mean, we have (a house). (Fausto)

House as a physical unit gives rise to the place where people can be found and where they spend

a good deal of time, especially at night, when they are not working or performing other daily external activities. It can also be considered that the division of the home's internal spaces indicates different functions, such as cleanliness, food, socializing, education, rest, and production space. The furniture and objects declare the financial situation and reveal peculiar characteristics of the inhabitants¹³.

In the case of people who experience severe psychological distress and have been hospitalized at some point in their lives, the fact that they have their address is fundamental for the exercise of citizenship. Thus, they can expand the aspirations of acquiring other goods with social values and expand their demands for quality of well-being, considering that it is possible to dream of an ideal home. These expanded desires are elucidated in some examples:

[...] a blockhouse... like a very comfortable apartment that had everything! Television, DVD, refrigerator, microwave, one person. (Álvaro)

I see a house with comfort, a house with a television, computer, microwave, refrigerator, DVD... I think about it, right? A house with comfort [...] in our space. Our home... the bed to rest, the place for us to have lunch, all that stuff! Which is our home, where we receive each other. Our refuge. (Álvaro)

A beautiful, functional house. A house that I can have plants, lots of plants, that I can take my granddaughters to so that they enjoy. (Gabriela)

Although the idea of protection and intimacy essentially marks the concept of a house brought up by the respondents, this notion also accompanies some projections and idealizations of a comfortable and welcoming space. In the reality studied, everyone wants to live in better facilities. Social functioning aspects are significantly associated with autonomy and ways of living¹⁴. While a house responds to a basic need, it seems that the desires of this group expand when confronting social limitations. House experiences are dynamic, and the privacy presented by their spaces indicates certain levels of freedom with transforming effects on the subjects' lives. Having your own space to live is like ceasing to be cared for, taking care of yourself, your belongings, and managing your life¹⁴. The reports point to the desire for one's own space, an intimate space where people can have their goods protected and correspond to their pleasures and needs just as they value having the freedom to express themselves freely and relate to other people.

Ways of living

Remarkably, persistent specters of the stigma that traverse the lives of former inmates of psychiatric hospitals are perpetuated even if they live in their urban homes. The Brazilian Mental Health Policy aimed to respond to housing concerns with the creation of SRTs and the PVC¹. Deinstitutionalization objectives have been under attack in recent years, and setbacks highlight several daily challenges for CAPS users. The reality of people who demand attention and care in mental health is being affected by political and administrative issues¹⁵. Consequently, we should emphasize the limitations in the field of work, income generation, exchange possibilities, and conditions for providing general expenses, besides food and other basic needs, amplified by intense psychological distress. Given the territorial characteristics, we can see the different housing conditions by region of the city. The rent for a room in a collective house (tenement) with an external bathroom can reach BRL 600.00 or more, as illustrated below:

It's a room... and I pay rent. BRL 600.00. (...) One room only, with an external bathroom. (...) I wanted more space... Things are very much on top of each other. It's a bedroom, not a house. (Carlos)

I think it's expensive. I am retired. Moreover, today, the minimum rent is more than half the minimum wage. (Gabriela)

The CAPS is located in one of the city's poorest regions and was the first service opened in the city back in 1989. It hosts residents of the hills, the stilt area, and the more populated suburbs. For those interviewed by this service, a house is seen as a protective space, leaving them exposed to violence and other residents of this region. Álvaro reveals that he is waiting to receive the Continuous Cash Benefit (BPC) to move. In his statement, he highlights structural violence that elucidates the daily lives of people living in similar conditions.

...We have favelas there. There are many drug dens, so there are many drug dealers. There's shooting, and I get scared. The people there are all a bit scared because the police are constantly patrolling there. Then it confuses us working people with thugs (...) Moreover, there is an alley. It's hell! [...] So, the police invaded my house there, they searched my brother-in-law [...] There was a time when I was at home like that... and then the police officer caught me by the neck and dragged me, almost killing me by choking, and my brother seeing... doing nothing! The police used to go straight

in there, to catch criminals... now they're not going in anymore. (Álvaro)

Unlike this experience, participants received by CAPS located in an affluent region report another reality. In contrast, those who want a blockhouse and have "basic" appliances would like to live in a place with more access or possibilities. Two respondents live in neighborhoods in the coastal region and describe a more significant increase in social interactions and exchanges. One reports that he lived with his family before falling ill and he lost his assets after falling ill. Today, retired due to incapacity for work, he started to live in a pension. A respondent lives in her apartment in a housing complex with her child, grandchildren, and great-grandchildren. Violence is not mentioned, and her needs are wishing for improved housing conditions.

Look, I could live in a better place, ok? Closer to the beach. I live in Macuco. It's a place like any other: it's far back. Far back is not cool! There's nothing to see. If it was closer to the beach, I could stay closer to the beach and go for a walk. I get tired too, you know? So, I stay indoors watching television. (Fausto)

I live with my son...my mother passed away, and so I live with my son. My son lives with me; the apartment is mine. Furthermore, I have two grandchildren who live together too. I raised the two grandchildren. It is BNH, a three-bedroom apartment, and has a large living room. I stay in one room, and my grandchildren and great-grandchildren stay in another room- my son on the other. I want to live alone...because they give me much trouble, much concern. (Eliana)

Two CAPS are located in the territory close to each other and with similar realities. In general, users of these CAPS reside in rented rooms in a pension or tenement, with their families or alone. One user reported that she worked and lived in a better house before the illness process. Currently, with limited financial resources, she started to live in a room in a collective house.

For example, that collective housing... I live in one! I would like them to be places of brotherhood, dialogue, openness, but it turns out that they are not, right? I think this exists everywhere, but collective housing, well... some have a very perverse dynamic. We have rooms with a bathroom and rooms without a bathroom. Mine has no bathroom in the room. It's collective. (Gabriela)

The spatial configurations of dwellings show features resulting from social inequality. Thus, the housing need is confronted by the insufficiency of spaces, making housing demands an

organization that adapts to the available concrete space¹⁶.

At home, we don't have anything to eat. So, I get a basic food basket, and I take it home. Then, things are missing: we have bills to pay, you know? So, all that stuff, we got upset. It's the electricity bill, the water bill, and the gas cylinder. We got very sad. [...] when I go to sleep, my room has nothing. I wanted to have a television, a radio [...]. I keep thinking, "Gosh! I don't want to live at home anymore. Sort of, having my little space, got it?" (Henrique)

Ivan also resides in a shared room typical of the city's tenements. He has no appliances or space for cooking. Like all residents, he uses the outdoor shared bathroom. Together with Henrique and Joana, he has his daily meals at the CAPS and goes there for his physiological needs, as he has a space with a bathroom and clean, private facilities. In these cases, housing limitations lead people to resort to the CAPS for essential needs, given their precarious socioeconomic conditions.

These aspects contribute to unveiling how the material conditions affect the other dimensions of the subjects' lives and are transmuted into inhibiting subjective conditions for urban living. Thus, the CAPS responds to shortages intrinsic to the housing issue, besides the social, economic, and cultural factors. These needs are in different spheres of life with a strong relationship between housing demands in interface with mental health¹⁷. In an analysis of scenes of circulation through the neighborhood and expansion of access to commercial, health, and cultural services, we observed that appropriation and reappropriation of the body, house, and street occur differently as of living. Thus, we can consider that purchasing power, house location, and meetings with other people establish new ties and social constructions that become fundamental circumstances for the consolidated living in the city¹⁸.

Regarding the CAPS located in the central region, as it accommodates many residents of the tenements existing in the territory, the dimension of housing is a common dilemma in the therapeutic plans built with users. The housing conditions in tenements are illustrated in the following report:

It's one room... I pay rent. (...) I pay for the bathroom... which is not collective, just for my wife and me. BRL 600.00. (...) I like it, but I don't intend to spend the rest of my life there. (...) I wanted more space... Things are very much on top of each other. It's one bedroom, not a home that I would choose (Carlos).

These users' ways of living in this territory are similar in several aspects. In general, the lack of financial resources imposed by the limited work possibilities and other income-generating activities and weakened family ties make these people have similar housing conditions regarding physical spaces (pensions, tenements, and working-class homes) and access to scarce material resources. As an element of human life, it is essential to highlight that these ways of living are essential factors for psychosocial rehabilitation and the care of psychological distress when related to greater or lesser inclusion in society¹⁹. Even considering the adversities, a house is a space that ensures protection, which is observed when these people relate the house to a safe place:

I believe that as bad as the space [even collective] can be, it's better than staying on the streets. Because what does staying on the streets mean? Shorten life because there's no rearguard there and no peace. There they cut their hair, take people to bathe, and toss them on the streets again. In some places, homeless people are repressed, so I don't think there is a worse situation than homeless people. (Gabriela)

The CAPS emerge as an extension of housing in some situations, reflecting its importance as a response to the concrete absence that permeates housing and a fundamental right such as food. It is also demarcated as an essential space for exchange, affection, and care, similar to what they expect from a house. While it is not exactly their role in mental health policy, we can observe that they are responses to the housing needs of users. CAPS also emerge as a place of support for those who need to live independently and address several challenges by daily life in society, asserting themselves as an essential locus of care and protection for these individuals.

Relationships with space and the territory

Although people have several limitations in their homes, it can be said that these spaces offer pleasure and coziness. When they arrive home, people know that they have a protected space to themselves, regardless of objective characteristics, as indicated in the reports below, by valuing the activities performed daily:

I take care of the dog, clean my floor. (...) I like to cook. My son cooks. (Eliana)

When I'm home, I like to cook, make some noodles, make rice. Furthermore, when the food is ready, I just heat it in the microwave. (Henrique)

Read, watch TV, rest. I'm constantly fiddling with something... (Gabriela)

I like that there's a bar close by, a grocery store... I go there. I can have a soda; once in a while, I have a non-alcoholic beer. (Carlos)

The physical space denotes the possibility of occupying, organizing, decorating, and experiencing the house in plural and private way, responding to personal desires. Social identity is closely linked to the freedom to express oneself and the decision-making power of actions²⁰. Inside their homes, they (re)organize themselves and exercise their autonomy and individuality in a more flexible or limited way – depending on the relationships in their daily contexts¹⁹. Thus, the exercise of exchanges and social values that demarcate a construction of autonomy can be observed when Carlos says that he likes living near a bar and grocery store.

Crossing the territory allows people to build a path in which tastes, preferences, and desires can be expressed, circulating in the neighborhood where they live and savoring what they want¹⁸. This is an example of how daily exchanges take place in the smallest details, especially for those with a history of institutionalization, as in the case of Carlos, who, during interviews, values his home by remembering the past marked by hospitalizations and electroshocks: “There at my city, I was admitted to the asylum. [...] I received a head shock almost every day.” The neighborhood and the traffic on the streets surrounding the house allow a feeling of belonging as a citizen. It is possible to cross the walls of the personal domain towards citizenship, experiencing situations of unprecedented encounters and discoveries favored by exchange relationships²¹. Contrary to the exclusionary societal model in which the individual is simplified through a diagnosis, inhibited in his relationships, the history of hospitalizations emerges as a watershed that affects the social position, public image, and other life aspects.

Living in the city points to a series of experiences common to everyday life in the city. While these respondents live intense psychological distress, they are cared for in the territory and can create bonds, recreate spaces, and thus recreate their relationships as well; they also experience some restrictions. While possible exchanges exist, they are often limited, which can be evidenced by pointing out the few social interactions in the territories, such as circulation in local businesses and bonds with some people in the neighborhood. When analyzing relationships broadly, we can observe that relationships with people and activities offered by the CAPS are frequent. This

characteristic highlights the affective relationships established between workers and users as a space for life experimentation and the expansion of bonds of friendship and affective relationships with people with whom they identify²², affirming living with solidarity and friendship.

As for family relationships, the freedom they have to use spaces, goods, and receive visits, for example, are linked to relationships with the other house residents. We observe that the possible appropriation of the house is also reduced in the face of weakened family ties.

My sister says I live with her... I sleep at her house: it's different! I just sleep! Later in the morning, I shower at her house, but now they put my shower. (Beatriz)

Even after years of living with her sister, Beatriz considers not residing, but just sleeping and bathing there, showing the low degree of belonging vis-à-vis her house. Spaces, furniture, and objects are not arranged at random. They correspond to the particularities of the residents' organization and expression, with different forms of use and occupation. Thus, it is also necessary to feel part of it²⁰ to take ownership of a house.

As a relevant aspect, the coastal tourist city allows a series of public spaces to attend, and even so, the respondents indicate that they do not cross these places, limiting the route to their neighborhoods, through shops, neighborhoods, and other familiar spaces. Respondents indicated that they arrange trips, go to the movies, or participate in cultural activities offered by the CAPS. The social interaction expands to promote participation in cultural and social activities, as observed greater circulation through the territory:

Ah, I like to play ball... I'm taking a graffiti course. (Álvaro)

Taking a bus and going to a place is incredible. Walking around Ana Costa is cool. I am very, very down to earth. I don't aspire to significant events. (Gabriela)

Public transport allows respondents to access different places and circulate across social spaces like any other citizen¹⁵. We can affirm that inhabiting the city reveals spaces for inclusion in their social rules, creating own spaces, and apprehending the rules of living when experiencing the house and its surroundings. The city starts to provide spaces for exchange and meetings through the movement across territories. If, for a long time, madness was isolated from the city through closed and controlled institutions, after the psychiatric reforms, the city can be taken over by madness again, consolidating the fight against

what was produced by asylum domination, as long as care is guaranteed in freedom.

Final considerations

While several contradictions have been observed, the understanding and visualization of the whole allow perceiving that most of these people have limited resources, poor housing, and troubled family relationships. The scarce material and financial resources make some users resort to the CAPS because of their limited conditions to pay for housing, food, and other fundamental needs.

Circulating through the city is limited, as users tend to walk through the neighborhoods closest to their homes and build relationships with local people. Thus, when shopping at local stores, riding a bus, or going to the CAPS, they establish essential relationships for exchanging messages, affections, and words. However, they report few bonds with the neighborhood. No specific actions of the CAPS teams were observed regarding direct work geared to housing, but some users' needs are met based on the physical structure and

external activities that the units and their teams provide. Another ambivalence observed is the appropriation of housing and territory. While the respondents refer to daily care activities with the home and what they like to do at home, they seem not to feel the freedom of choice, such as receiving visits or even cooking and report family complaints about the inconvenience they cause in small everyday acts. This information not elucidated in this paper highlights the need for further studies on relationships with family members.

We can conclude that, even with access to care in freedom, some gaps to make a life with social participation effective persist. Strengthening circulation across the city and the appropriation of spaces requires thinking about policies that encourage the increased inclusion of these people in urban life. A vital contribution to the promotion of these practices has been the loan of contractual power carried out by the technicians of the CAPS teams, in which, through external activities, they encourage the appropriation of the city's spaces, strengthening exchange relationships and coexistence with the most diverse people.

Collaborations

MM Stracini and MIB Moreira worked equally to prepare this paper, which derives from the Master's dissertation by the first author under the supervision of the second.

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Article submitted 30/10/2020

Approved 13/10/2021

Final version submitted 15/10/2021

Chief editors: Romeu Gomes, Antônio Augusto Moura da Silva