

Original Article

# Participation and autonomy of people who live in residential therapeutic services: contributions from occupational therapy<sup>1</sup>

*Participação e autonomia de pessoas que moram nos serviços residenciais terapêuticos: contribuições da terapia ocupacional*

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## Abstract

**Introduction:** Therapeutic Residential Services (RSTs) represented a great advance in the Brazilian deinstitutionalization process, but it is necessary to invest in discussions that contribute to these devices being powerful spaces for housing and for valuing the subjectivity of its residents. **Objective:** To investigate the participation and exercise of autonomy of residents of type II RSTs, based on their own perception. **Method:** This is qualitative, exploratory, and documentary research, carried out through the collection of documentary data and interviews. Eight residents of type II RSTs participated in the study. The material produced was submitted to thematic analysis. The concept of Daily Life underlies the study, from the perspectives of Occupational Therapy, the Theory of Daily Life by Agnes Heller, and Psychosocial Rehabilitation. **Results:** Prolonged institutionalization is closely related to the participants' little participation and autonomy in their daily lives, with little or no ownership of the SRT, and with the perception, they have of themselves as patients and not as residents of their homes. The exercise of autonomy by the participants is related to their performance and functionality in carrying out daily activities and pre-established comprehensive care for type II SRT. **Conclusion:** It was concluded that Occupational Therapy brings fundamental contributions related to the participation and autonomy of people who, due to prolonged institutionalization, are in an important situation of chronicity. Participation in daily activities and the possibility of exercising autonomy in the SRT is the first step towards the definitive possibility of social inclusion for its residents.

**Keywords:** Institutionalization, Mental Health Services, Occupational Therapy, Free will, Social Participation.

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### **Resumo**

**Introdução:** Os Serviços Residenciais Terapêuticos (SRTs) representaram grande avanço no processo de desinstitucionalização brasileiro. Porém, faz-se necessário investir nas discussões que contribuam para que esses dispositivos sejam espaços potentes de habitação e de valorização da subjetividade de seus moradores.

**Objetivo:** Investigar a participação e o exercício da autonomia dos moradores de SRTs do tipo II, a partir da sua própria percepção. **Método:** Trata-se de pesquisa qualitativa, exploratória e documental, realizada por meio de coleta de dados documentais e de entrevistas<sup>1</sup>. Participaram do estudo 8 moradores de SRTs tipo II. O material produzido foi submetido à análise temática. O conceito do Cotidiano embasa o estudo, a partir das perspectivas da terapia ocupacional, da Teoria do Cotidiano de Agnes Heller e da Reabilitação Psicossocial. **Resultados:** A institucionalização prolongada está estreitamente relacionada com a pouca participação e autonomia dos participantes em seu cotidiano, com a pouca ou inexistente apropriação do SRT e com a percepção que eles têm de si como pacientes, e não como moradores de suas casas. O exercício da autonomia pelos participantes é relacionado ao seu desempenho e funcionalidade na realização das atividades diárias e à assistência integral pré-estabelecida para o SRT tipo II.

**Conclusão:** Concluiu-se que a terapia ocupacional traz contribuições fundamentais relacionadas à participação e à autonomia de pessoas que, devido às institucionalizações prolongadas, encontram-se em situação importante de cronificação. A participação nas atividades cotidianas e a possibilidade do exercício de autonomia no SRT são o primeiro passo rumo à definitiva possibilidade de inclusão social de seus moradores.

**Palavras-chave:** Institucionalização, Serviços de Saúde Mental, Terapia Ocupacional, Autonomia, Participação Social.

## **Introduction**

The Therapeutic Residential Services (*Serviços Residenciais Terapêuticos* - SRTs) are devices of the Psychosocial Care Network (*Rede de Atenção Psicossocial* - RAPS), which aim to enable people with psychological distress to live in society. The SRTs are classified as type I and type II, according to the commitment and need for supervision of their residents, being intended for people with more independence and for those with greater commitment, respectively (Brasil, 2004).

Living in an SRT enables one to be in the community and access basic citizenship items such as personal documentation, social benefits, food, clothing, among others. However, this is just the beginning of the process of desinstitutionalization of its beneficiaries. Together with other devices in the mental health care network and

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through the continuing education of its professionals, it has the potential to promote the social inclusion of these people.

This debate is necessary to advance in the discussions about the SRTs and about the social inclusion of their residents, which means much more than living in the community and having access to items that they did not have in the psychiatric hospital. Salles & Barros (2013b, p. 1060) understand social inclusion as the possibility of leading one's life and experiencing it in all its power. They defend that "social inclusion is a process of promoting rights, access, choices, and participation". Discussing this subject, therefore, presupposes paying attention to two fundamental aspects that are inseparable parts of the social inclusion process, which are the participation and autonomy of people who live in the SRTs.

The difficulty observed in the case of people who are chronic and have numerous limitations due to prolonged institutionalization is that social participation ends up being non-existent or scarce. Also, when it happens, it is carried out under the supervision of professionals who work with these devices, mainly through a definitive perspective established as to the limitations of this subject. Thus, even participation in activities of daily living becomes a supervised aspect, not encouraged to be carried out independently and to enable individualization and the subjective expression of the residents' desires and interests, even for those who are able to carry them out.

In this sense, occupational therapy has a lot to contribute, as the issue of participation and autonomy permeates not only the micro aspects but also the macro-social ones. According to Galheigo (2020), through a critical perspective of the practice of occupational therapy, the articulation between these micro and macro-social aspects is woven; individual and collective are understood in a connected way.

The practices of occupational therapy, in a critical perspective, today, in our view, call for listening, welcoming, dialogical encounter, social and network articulation, and the construction of therapeutic and life projects with those who need and/or they claim to care, support, a decent life, social participation and access to rights (Galheigo, 2020, p. 14).

Silva & Oliver (2019) carried out a systematic review of the concept of social participation used by Brazilian occupational therapists and referred to the multiplicity of understanding and use of this term. For them, social participation is understood as:

The involvement of subjects in social groups and/or in public and community spaces, to transform daily life and living conditions marked by illness, violence, mental and/or psychological suffering, social and occupational injustice, inequality, prejudice, exclusion, and oppression. It is a definition circumscribed in the field of sociology and occupational therapy to understand it as a political and emancipatory practice, which takes place in social, political, economic, and cultural contexts, at the micro and macro-social levels (Silva & Oliver, 2019, p. 859).

Social inclusion is closely related to participation both at the micro and macro social levels. However, in the case of people who live in type II SRTs and who, a priori, need more help, reflecting on participation and autonomy in activities of daily living is the

necessary first step to achieve effective social participation. Occupational therapy plays a fundamental role, both in this more individual action, for the subject's participation inside the house, for example, and in his dialogue with the community. In this case, using the definition of Silva & Oliver (2019), we can think of an action that starts at the micro-social level, to, together or later on, stimulate the process of participation of these people at the macro-social level.

The literature review in the area pointed out that studies on the housing perspective mostly dealt with the perception of employees and the community around the residences on the SRT. Those that evidenced the residents' perception about this aspect focused on the social network established by the residents inside and outside the house, their possibility of freedom and power of choice, and their perception of care and health within the SRT. It is important to highlight that, those studies found that mentioned the type of SRT investigated, only 1 stated that they had residents of type II SRTs as participants. According to Salles & Miranda (2016, p. 370), in the context of national and international research on the deinstitutionalization of psychiatric patients, "[...] there is little data on the social and psychological dimensions of these subject's' reintegration".

This study aimed to investigate the participation and exercise of autonomy of residents of type II SRTs, based on their own perception. This is an excerpt from a master's research whose general objective was to understand the perception of people who live in Therapeutic Residential Services about their daily lives and presented the analysis of the results through five thematic categories: Life inside the house; Life in the territory; Me in life; What to do in life; and Life and the future. We will introduce the first category. It is important to clarify that the analysis is limited to the report of the participants, not considering the view of professionals, managers, and others involved in the SRTs, as this study already aims to the partial character of investigation, focused on the residents of these devices.

## **Methodological Path**

This is qualitative, exploratory, and documentary research carried out with 8 people who live in 3 SRTs of type II, in the municipality where the study was carried out. Residents of four SRTs with type II in that municipality were invited to participate in the research. As established criteria for participation in this research, it was necessary for them to respond by themselves (not to be curated), to be independent in activities of daily living, with preserved verbal communication, to accept to participate in the research and to sign the Informed Consent Form (ICF).

The research was divided into 2 phases: the first consisting of document data collection; the second through interviews. In the first phase of the study, data was collected from reports, documents, and other information found in the medical records filed at the CAPS located in the interior of the state of São Paulo. CAPS is a reference for the SRTs in the municipality where the study was carried out. It aimed to characterize the participants. A personal information form was used, containing personal data (name, age, marital status, education, work experience), hospitalization/institutionalization history (date and periods of hospitalization, reason, diagnoses received, medications used) and social history (documentation, receipt of

social benefits, family and affective bonds) to aid in the registration and organization of data.

In the second phase, semi-structured interviews were carried out following a pre-established script by the researcher, with 6 blocks of open questions (about life in the SRT, about what the SRT represents in life, about what activities and relationships represent in life, about life in the SRT and in the psychiatric hospital, family/affective bonds and current life in the context of the coronavirus). It aimed of identifying and understanding how they perceive their daily lives and how they have lived their lives in the SRTs.

As a result of the COVID-19 pandemic, since April 2020, entry into therapeutic residences is now restricted to employees of each household and in emergency situations. Thus, the interviews were conducted online via video call via the WhatsApp application. As only one research participant has a cell phone, and all the others are unaware of or have difficulty handling such resources, we counted on the collaboration of the employees of the SRTs in sharing their cell phones for the interviews.

Data from the interviews were submitted to Thematic Analysis, having been extracted themes that were gathered and organized in five categories: Life inside the house; Life in the territory; The self in life; What to do in life; and Life and the future. In this article, we will present the thematic category called “Life at home”, with a focus on participation and autonomy, which were predominant aspects in the participants' reports.

## **Results and Discussion**

Unanimously, the SRT was evaluated as a divisor, a milestone, a beneficial transformation in the lives of the participants in this study, both for the possibility of access to basic items of citizenship and for the security, mentioned by them from the perspective of physical protection and welcoming. However, we observed that, the greater the chronification, the more homogenizing the daily practices become; the house's routine loses its individualized character and becomes a determined sequence of tasks to be performed by employees, done in the same way for everyone. We observed that the SRT emerged as a symbolic, subjective and affective power from the perspective of the participants, mainly due to the relationship of affection and care established between them and the professionals of these devices. But there are elements brought by them about their daily lives regarding their participation and exercise of autonomy that are still linked to guardianship and assistance. Psychosocial Rehabilitation advocates that one of the axes on which the increase in contractual capacity is built (which presupposes the exchange of goods, messages and affections between people) is housing; not only in the material sense of being in a house, having shelter, but of material, symbolic and affective appropriation of this space by its residents. Therefore, we argue that the SRT is understood as a house, which is part of a set of strategies aimed at increasing the possibilities of exchanging resources and affections between people.

By checking the medical records of the participants, which are stored in the CAPS as a reference for the studied SRTs, we could characterize them based on social, personal and family, clinical data and hospitalization/institutionalization history. It is important to highlight that the discharge reports from the last psychiatric hospital where they were hospitalized are filed in the respective medical records and were also consulted to compose the data collection. Figure 1 presents the characterization of the research participants.

PARTICIPANT	GENDER	AGE	ORIGIN	MARITAL STATUS	EDUCATION LEVEL	OCCUPATION
P1-JOÃO	MALE	28	SÃO BERNARDO DO CAMPO	SINGLE	INCOMPLETE HIGH SCHOOL (ATTENDING EJA)	NOT INCLUDED
P2-ROSA	FEMALE	69	NATIVIDADE DA SERRA	MARRIED	ILLITERATE	NOT INCLUDED
P3-MARIA	FEMALE	57	PALMEIRA D'OESTE	SINGLE	LITERATE	NOT INCLUDED
P4-JOSÉ	MALE	61	SOROCABA	COMMON-LAW MARRIAGE	INCOMPLETE ELEMENTARY EDUCATION	RETIRED DUE TO DISABILITY (WORKING AS A BRICKLAYER)
P5-JUREMA	FEMALE	60	SÃO PAULO	SINGLE	NOT INCLUDED (BUT SHE CAN READ AND WRITE)	NOT INCLUDED (HE REFERS TO HAVING WORKED AS A MAID)
P6-ANA	FEMALE	83	SALTO DE PIRAPORA	WIDOW	ILLITERATE	MAID
P7-RITA	FEMALE	69	TATUÍ	SINGLE	ILLITERATE	RURAL WORKER AND MAID
P8-CLÁUDIA	FEMALE	48	SÃO MIGUEL PAULISTA	SINGLE	ILLITERATE	MAID

Figure 1. Characterization of participants. Source: elaborated by the author from the documentary research.

Figure 2 shows the history of admissions and the institutionalization situation of the participants.

PARTICIPANT	TOTAL HOSPITALIZATION TIME	HOSPITALIZATION PERIOD	REASON FOR ADMISSION	DIAGNOSIS	OTHER RELEVANT INFORMATION
P1-JOÃO	3 YEARS AND 6 MONTHS	2012	BEHAVIOR DISORDER AND ABUSE OF PSYCHOACTIVE SUBSTANCES	NOT INCLUDED	A REPORT OF THE MUNICIPALITY'S SOCIAL SERVICE IN 2013 REQUESTED THAT HE CONTINUES TO BE HOSPITALIZED FOR NOT HAVING FAMILY SUPPORT. HE HAD ALREADY BEEN DISCHARGED.
		2013-2016	BEHAVIOR DISORDER AND ABUSE OF PSYCHOACTIVE SUBSTANCES	F20.0 (PARANOID SCHIZOPHRENIA) F06.2 (ORGANIC DELIRIOUS DISORDER)	
P2-ROSA	34 YEARS	1982-1992	ABSENCE CRISIS	NOT INCLUDED	SHE DID NOT USE MEDICINES. SHE HAD NO IMPORTANT PSYCHIATRIC OR CLINICAL DIAGNOSIS
		1992-2016	REFERRAL TO ANOTHER PSYCHIATRIC HOSPITAL	F07.0 (ORGANIC PERSONALITY DISORDER) F 99 (MENTAL DISORDER NOT SPECIFIED)	NOT INCLUDED
P3-MARIA	15 YEARS	2001-2016	PROBABLE SOCIAL ABANDONMENT	F20.5 (RESIDUAL SCHIZOPHRENIA)	SHE HAD SEVERAL PRIOR ADMISSIONS, BUT THERE ARE NO REPORTS.
P4-JOSÉ	11 YEARS*	1989, 2008, 2011, 2015	COMPULSORY ADMISSION	F10.2 (MENTAL AND BEHAVIORAL DISORDERS DUE TO THE USE OF ALCOHOL)	HE HAD SEVERAL PRIOR ADMISSIONS, BUT THERE ARE NO REPORTS.
P5-JUREMA	36 YEARS	1980-2016**	FORWARDED FROM CETREM (CENTER FOR SCREENING AND REGULATION OF EMIGRANTS) IN SP.	F70.3 (SLIGHT MENTAL DELAY - SIGNIFICANT BEHAVIOR COMMITMENT, REQUIRING SURVEILLANCE OR TREATMENT)	SHE WAS AT FEBEM UNTIL THE AGE OF 16. HISTORY OF ADMISSIONS AFTER LEAVING FEBEM, BUT THERE ARE NO REPORTS.
P6-ANA	35 YEARS	1981-1985	FORWARDED FROM CETREM (CENTER FOR SCREENING AND REGULATION OF EMIGRANTS) IN SP..	NOT INCLUDED	NOT INCLUDED
		1985-2016	PERSECUTORY DELIRIAL IDEAS, AGGRESSION, AGGRESSIVENESS, BEHAVIORAL DISORDERS	F20.5 (RESIDUAL SCHIZOPHRENIA)	NOT INCLUDED
P7-RITA	41 YEARS	1975-2005	NOT INCLUDED	NOT INCLUDED	THERE IS NO REPORT FROM THIS PERIOD
		2005-2016	FORWARDED FROM ANOTHER SERVICE	F70.0 (SLIGHT MENTAL DELAY - ABSENCE OR MINIMUM COMMITMENT OF BEHAVIOR)	NOT INCLUDED
P8-CLÁUDIA	25 YEARS	1991-2016	FORWARDED FROM CETREM (CENTER FOR SCREENING AND REGULATION OF EMIGRANTS) IN SP.	F31.1 (BIPOLAR AFFECTIVE DISORDER - CURRENT MANIAC EPISODE WITHOUT PSYCHOTIC SYMPTOMS) F07.9 (UNSPECIFIED ORGANIC DISORDER OF PERSONALITY AND BEHAVIOR DUE TO BRAIN DISEASE, INJURY, AND DYSFUNCTION) G40.8 (OTHER EPILEPSIES)	HAD EARLY HOSPITALIZATIONS AND PASSES AT FEBEM

Figure 2. History of admissions/institutionalizations. \*Total time of stay in a psychiatric hospital. In the report only the years in which entry into compulsory admission was given, with no discharge date. There is only the sum of these 4 periods, which is the equivalent of 11 years of hospitalization. \*\*Period of psychiatric admission only. The period which stayed at FEBEM does not contain in the reports or in the records.

It is important to mention that the SRTs were heterogeneously constituted, not necessarily following the condition of dependence and need for assistance of their residents. This is because other factors were taken into account in the composition of the people who would live in the four residences established in the municipality where the study was carried out, with affective ties and friendship between them, and/or having been born and lived in this city, for example.

Through the interviews, we understood the trajectory of each one and their life stories, noting that, in the participating SRTs, homogenizing care practices still prevail, little encouragement for the participation of residents in daily activities. When it occurs, it assumes a character of help to the SRT professional; autonomy is an aspect that does not even reach the reflection and discussion of professionals and the residents themselves. There are some hypotheses for this: the lack of mental health training of professionals, who mostly had only work experience in a psychiatric hospital and general technical training, as is the case of hired nursing technicians; the predetermined and expected characteristics for people who are destined for a SRT type II, which lead to assistencialist and/or directed actions, since the subject's capacity is predetermined as limited, which needs more help; and the confusion of understanding what limitation and chronification are, favoring behaviors that maintain the stagnation of the SRT resident. Considering that the average length of stay in a psychiatric hospital of the participants was 25 years, participation and performance in activities is quite impaired, but this situation is still linked only to the subject's conditions and not as a result of this history of prolonged institutionalization.

We will discuss here the category "Life at home" based on the themes: (Re) learning how to do, like and want: participation in discussion; and (Re)thinking the limitations: autonomy under discussion.

### **(Re) learning to do, like and want: participation in discussion**

In order for the subject to participate in daily activities, it is necessary, initially, the possibility of his insertion in the world, through contact and experience; then, its action (regardless of whether it is carried out with or without assistance, in a total, partial or adapted way); one can evolve, thus, towards a knowledge of oneself (through the things he likes or not to do) and to a knowledge of the world (through the understanding of relationships, of the things that exist, of how they work); which, finally, will return to the subject in the form of a desire to perform or learn such activities. Thus, participation presupposes the subject's involvement and engagement in their daily lives.

The concept of participation used in this article dialogues with that of the American Occupational Therapy Association (2015, p. 4), which understands participation as the active performance of subjects in "occupations or activities of daily living in which they find purpose and meaning", which subject's involvement in this process encompasses its objective and subjective aspects. In this sense, participation involves action, exchanges, involvement, in addition to the meaning and desire for the subject who performs it. It is important to emphasize that this definition covers, in a more limited way, participation in the sense of activities of daily living. Therefore, the definition by Ferreira & Oliver (2018) was also considered, who understand social participation

through the various dimensions of the subjects' lives, in a broader way. For them, social participation is defined as the

[...] access and involvement in everyday activities and citizenship, such as study, work, leisure, and cultural activities, political activities, among others; as well as the establishment of social relationships, whether within the family, friends, or affective relationships (Ferreira & Oliver, 2018, p. 750).

Research participants mentioned the use and appropriation of the SRT, which, recurrently, is limited to the concrete and objective use of spaces, equipment, and devices, in addition to how little opportunities and/or resources exist for the subject to experience possibilities of creation and subjectivity in the SRTs. This is a factor markedly aggravated by prolonged institutionalization.

We extracted excerpts from the interviews carried out with the research participants that helped in the analysis. Their life stories highlighted the meanings of carrying out activities for them, which were forgotten due to prolonged institutionalization. The reports showed the perception of no longer knowing how to do some activity and not even knowing what one wants, or what one likes, evidencing the resulting chronicity. They mentioned the lack of opportunities for active participation in-home care activities, for example, and the extent to which the employees' role as holders of power still exists, in addition to the perception of themselves as patients. In this way, the idea of help and not appropriation prevails in the reports, as well as in the psychiatric hospital. The subjective appropriation of the house and its housing appeared for only 2 research participants. There was a trend towards the homogenization of practices carried out in the SRTs, which, added to the chronification resulting from prolonged institutionalization, result in little participation of people who live in these devices in their daily lives.

Thus, in this clipping, participation was divided into 3 aspects that were highlighted most frequently by research participants and that are directly related to this factor, and which will be presented below: Life stories and the meanings of doing, the importance of the experience, in addition to roles and attributions in the SRT. Possibilities for directing therapeutic-occupational interventions in this context will also be discussed.

### *The life stories and the meanings of doing*

The importance of understanding the life stories of people who have been in prolonged hospitalizations and currently live in the SRTs enables to differentiate between what is chronification and what is the limitation of each subject. Rosa and Ana report that they cooked before being admitted to a psychiatric hospital, but they forgot how to do it. Both had an uninterrupted period of hospitalization, of 34 and 35 years, respectively.

*I liked to cook too [...] Pasta. [about the desire to cook at the SRT] Now I forgot (Rosa).*

*I knew how to cook, but I haven't cooked for thirty years. The only thing I know how to make is pumpkin sauce [...] It's been so long now that I forgot, I don't even know how to add water to rice (Ana).*

For them, the “impossibility” of cooking is due to not using this skill over the years, and not due to a physical and/or cognitive incapacity that prevents its performance. In these cases, there is an evident chronification resulting from prolonged institutionalization. None of them cook at SRT, not even some quick preparation for themselves.

It is important to highlight that the meaning that each person attributes to the activities is fundamental to guide practices that really value their subjectivity. Ana, for example, says that she prefers to eat food made by the employees, as she has already cooked a lot for others throughout her life, as she worked as a maid. She mentioned the special preparations of things she loves to eat, like the pumpkin sauce; this one she still remembers how she does it. Thus, encouraging her to cook every day would have no meaning to her right now. But Rosa, on the other hand, did not even consider this possibility, nor was she offered the opportunity to cook. Neither of them has any physical and/or cognitive impairment that prevents them from performing this activity.

People's life stories are important conductors of the path to be followed in any care practice, to understand the meaning of a given activity for that person, and what their abilities, interests, and limitations are.

### *The importance of the experience*

Research participants are residents of type II TRS. According to the law, it is intended for those people with a greater need for help and supervision in daily activities. It was evident how much this also ends up determining a pre-classification of the amount of help that must be offered by professionals in these places, who end up performing all the tasks. José's account shows how the management and organization of the house become part of the employees' workflow and loses its routine and unique character that should be part of the daily life of the SRT residents.

*These people do everything, right? [about the SRT employees] (José).*

In these SRTs, we argue that the lack of mental health training of these professionals, who often came from experiences in psychiatric hospitals and end up reproducing the asylum logic in the SRTs, impacted the reports brought by the participants, who mentioned the lack of encouragement and openings for carrying out home care activities.

*[about activities performed at the SRT]. I help dry the dishes [...] Wiping them, they do it, they cook too (Rosa).*

*I don't help, because whoever cooks, already wipes the house, right? Then there's nothing else to do (Ana).*

Both Ana and Rosa understand that they are only responsible for helping, and they wait for the employees' request and authorization to carry out any activity at home. Thus, the possibility of experience is at the sole discretion of the professional. Hence the importance of offering and providing varied experiences to residents of the SRTs, so that they can then manifest and act more actively in their daily lives. It is the action, the experimentation that enables the (re)discovery of the subjects of their interests, desires, and preferences.

### *The roles and assignments*

Like Ana and Rosa, Cláudia also mentions her perception of the existence of roles and attributions in the SRT, evidencing the lack of a feeling of living in this house, which prevents her from feeling belonging, owner, empowered to take any initiative. There are indications that her view of herself is understood as a passive, patient being who needs guidance to perform some activity.

*Yes, when you need it, when it's really refined, I do help. For example, if the person who works here is doing one thing and asks me to do something else, I do it [...] I just sit, it's not because of laziness. Here, everyone has their job to do. So one cleans the bathroom, each one has its function here. [about your role in SRT] Mine? None so far (Claudia).*

Perhaps, through this reflection, it is also pertinent to evaluate the classification established for a type II SRT. In the research, we observed how much there is heterogeneity in the constitution of the participating SRTs, but it is also essential to assume that this heterogeneity is part of any SRT, whether type I or II. It is necessary to raise this discussion that the classification of an SRT is only to facilitate the planning of this device, and not to guide what should be expected from the performance of each resident or to determine the attributions of each one within the house.

In the interviews, the nomenclature used by the participants reinforces this aspect. Employees were appointed as bosses, caregivers, as those who have ownership and control of medication, money, and any and all decisions. Participants named themselves and others as patients. The perception of the feeling of power mentioned by them is related to some situations, and partially to uniquely individual factors, such as the report of feeling empowered about part of the value they receive from their benefits, from that money that remains in their possession, in their hands. This is an important indication to be worked on in the SRTs, which is to reflect with residents and professionals who work in these places about what they understand to be the roles and attributions of each one in this context.

### **(Re)thinking limitations: autonomy under discussion**

In the participants' reports, we noticed that, even for those with less need for help and supervision in carrying out the activities, and who already carry out them independently, autonomy was the least prevalent aspect in their daily lives. Some excerpts from the reports will be presented, divided into 2 aspects highlighted most

frequently by the research participants and which are directly related: the barriers and limitations encountered by them and the encouragement, graduation, and adaptation of activities.

Autonomy is the individual's ability to make decisions for himself based on the information he has or has available. It is one of the principles of Bioethics and, according to Cohen & Salgado (2009), it indicates a process, a "gain" of freedom proportional to the varied constituent conditions of each subject. This proportional gain mentioned is a crucial element for understanding the exercise of autonomy, especially for people who live in a type II SRT. These authors define autonomy as

[...] the capacity of self-government, of free will as to the rulership of one's own destiny, in doing or not doing, going or not going, accepting or refusing and so on, granted little by little, by parameters biological and social interactions, which distance humans from animals and create the contours of their personality (Cohen & Salgado, 2009, p. 227).

For these authors, what happens more often in the case of people with severe psychological distress is the loss of autonomy, as their speech and actions are invalidated because they are automatically linked to the symptoms of their disorder. And this "apparent" impossibility of having autonomy perpetuates the subject's life, as well as the received diagnosis, which remains as a mark throughout their existence. The possibility of rescuing autonomy is not considered, this being an aspect that is consolidated, in most cases, as a permanent situation for the subject.

It is only possible to speak of autonomy when there is the possibility of participation; as this is an aspect that is still deficient in the reality of the studied SRTs, autonomy is not even part of the participants' daily lives. It is necessary to differentiate the two things: a person can be participative, or be placed in participatory situations, but not have the autonomy to choose and decide what they want; and it is also possible that another person has autonomy, but is not participatory, whether due to physical and/or cognitive limitations or due to physical/structural, economic, cultural and social barriers.

Participation says about action and autonomy over decision and choice. Both are developed by the subject, are construction processes, and can be carried out in stages, partially or totally. It is part of the human being, even in conditions of "normality", to have limitations in different degrees, depending on the task to be performed, more or less autonomy in their daily lives, depending on the stage experienced, the context, among others. Likewise, such reasoning should apply to people "deviant" from this "normality", in which the starting point should always be the possibility of experiencing their own life, so that possible aids and interventions in difficulties and limitations can be analyzed later, whether of action and/or decision. Certainly, already structured limitations should not be disregarded, but they should definitely not be the starting point when it comes to the participation and autonomy of the people with whom one intends to develop any process.

In line with this discussion, Kinoshita (1996) addresses the need to expand support and help that all people should have; in the case of residents of the SRTs, they do not depend exclusively on the professionals of these devices.

We understand autonomy as the ability of an individual to generate norms, orders for their life, according to the different situations they face. Thus, it is not a question of confusing autonomy with self-sufficiency or independence. We are all dependents; the issue of users is rather a quantitative issue: they depend excessively on only a few relationships/things. This situation of restricted/restrictive dependence is what reduces their autonomy. We are more autonomous the more dependent on so many more things we can be, as this expands our possibilities of establishing new norms, new orders for life (Kinoshita, 1996, p. 57).

Thus, the insertion in different scenarios of the community in which one lives and social participation generate new relationships and experiences for the resident of the SRT, enabling the construction of a path towards autonomy. As previously mentioned, the SRT is the beginning for the participation, appropriation, and sense of belonging of its residents, but it must have as its final objective the expansion of access to physical, personal, relational resources, among others, that are part of the territory.

Based on the study carried out, we observed the relationship made both by professionals and by the residents, between the subject's ability to perform (with complete independence and without assistance) and autonomy; both are compared as inseparable and equally proportional. In this way, the understanding that if the subject has any difficulty/limitation; therefore, he cannot exercise his autonomy.

*The only place I don't like to go is the farm [...] which has lunch... I don't like it, I like to stay at home but everything goes, every house goes, everyone goes, then I'm obliged to go [about the possibility of not going to the farm] But I can't stay alone, there's no one to cook for me (Ana).*

In Ana's case, she does not have any physical and/or cognitive limitations that prevent her from deciding whether or not to go to the year-end event, which is held annually between the city's SRTs, but she ends up going because no employee remains in the house during this event. She feels like she needs someone's care, specifically for cooking. She is independent in activities of daily living; she just does not cook. Considering that she really needs this help, other possibilities are not even considered, such as leaving the food ready for her to heat up in the microwave, for example. These impasses are important moments that can be used to discuss with the resident of the SRT what they want about a given situation, what they would like to do, show what is possible. In this case, as an example, explaining that no professional will stay in the house with her during these events, offer options and allow her to decide what she wants to do. It would be a good time to encourage the use of the tablet in the house where she lives, for example, to be used in situations where she will be alone, in case she wants or an emergency arises and needs help.

### *The subject's barriers and limitations in their daily lives*

In the participants' reports, there was a recurrent mention of diagnoses and restrictions obtained while in the hospital, and of situations that occurred in moments of a disease crisis. Cláudia refers to situations that occurred when she suffered from

constant epilepsy attacks. Since she moved to SRT, she has not had any; however, she maintains the same restrictions.

The predominant logic observed in the context of the study is that either something is done entirely by the subject or it cannot be done. It is possible to see that these limitations begin to form part of the subject's condition, forgetting the fact that the environment is also a factor that strongly interferes with the limitations that a subject may have.

*I can't stand by the stove because I got burned on the stove. This burn was not here, it was in my employer's house [...] it was third degree. I don't forget to this day, I was making rice. I put the water on the fire because it says that with hot water the rice comes out faster, right? So I put the water on the fire. Then, in a little while, I had a crisis, it was the first crisis that had happened to me, then the boiling water fell all over me. When I woke up I was already in the hospital. No wonder I live under medicine [about the possibility of using a stove again] I'm prohibited, the doctor forbade me (Cláudia).*

In addition to epilepsy, Claudia has hemiplegia on the right side of her body. However, this limitation ends up extending to a large part of the activities carried out in her daily life and she does not participate in numerous tasks around the house. She refuses to carry out these tasks herself, as she believes she cannot.

In general, barriers are aspects that are more evident and that end up being part of the reflections related to SRTs, especially physical and cultural barriers. The accessibility and safety of the house in which the SRT will be installed, access to the various spaces in the city, and acceptance of the surrounding community are considered. But reflection on the limitations resulting from chronification due to prolonged institutionalization is in the background; one does not think about the limitations established in the period of hospitalization and how much they were related to the situation or resulting from the hospital environment and the long period of institutionalization.

### *Encourage, graduate and adapt activities*

Regarding the stimulation of activities, some factors were found in the study that were directly related to the participation of residents of the SRTs in activities in their daily lives: the burden of caregivers, the lack of guidance for new possibilities for the subject's participation, in addition to assimilation chronicity and limitations established throughout the life story of these people, as mentioned above. The first two factors are closely related, as the lack of training and knowledge of the role of the SRT end up centralizing the performance of all activities in the house and caring for the residents for the professionals who work in these places, in addition to not knowing how to promote increased participation by residents. Finally, the question of how to see these people, through the lens of deficit and limitation, is related to thought patterns that are crystallized through stereotypes that are maintained over time and that result in the perception that they cannot or are unable to perform certain activities.

It is an important role of the occupational therapist, in the individual aspect, more than investigating - together with the subject and in their daily lives - what their

limitations are, it is mainly to investigate what their interests and potential are. From that, to seek new possibilities of participation, which can be carried out in a partial and gradual way, with or without help, with or without the use of devices and increasing the difficulty of the activity according to the subject's progress and interest. It is important to highlight that the desire and interest, or lack of it, to perform any daily activity changes according to the period of life in which the subject is experiencing, according to the environment, stimuli, physical, cognitive and emotional health condition, among others. Therefore, these actions of stimulation, graduation and adaptation of activities must be constantly reviewed with the subject.

In the collective aspect, the occupational therapist's action has an important role in the reflection and debate of stereotypes, which are immense, of people who have lived a large part of their institutionalized lives. This is a factor that contributes so that the actions carried out by these people are always supervised and controlled in some way, and the character of their actions always end up taking on the role of helping another person, in this case, the professionals of the SRTs, or being strictly individualized. This articulation between residents for actions and collective responsibility for everyday life is also part of the occupational therapist's action, and also goes through processes of stimulation, graduation and adaptation for its performance.

Jurema is quite independent in her activities and mentions the desire to carry out other tasks that she does not perform yet. Despite having cognitive and physical conditions, he completely performs only a few activities from start to finish, especially those that are closely related to her individuality, such as preparing instant noodles that he wants to eat, receiving and managing her money to buy clothes and some food items. She states that she would like to carry out an entire task around the house. She already washes some of her clothes by hand and helps with parts of this task, such as taking the dirty clothes out of the hamper, but she still does not know how to use the washing machine.

*What I wanted was to learn how to use the machine, so Sol and I could wash our clothes [...] (Jurema).*

Despite her physical limitation, Cláudia does not have any commitment that makes it impossible for her to learn to use home appliances and electronic equipment independently. Her favorite pastime is watching movies, soap operas, and shows on television. When she wants to watch something specific, she asks an employee of the house to look for it for her.

*Here, I wash clothes in the machine [...] I don't know how to handle anything, not even on the TV, I don't know how to turn on the television, or turn on the music, I know (Cláudia).*

It was possible to see how much there is a need for this topic of participation and autonomy to be constantly reviewed, as they tend to be incorporated into an automatic routine, in which the fact that the SRT resident does something during the day ends up being considered sufficient.

## **Final Considerations**

The intervention in occupational therapy goes beyond the individual process of the subject in their daily life, as it also involves a process of articulation of teaching and mutual learning between the residents of the SRTs, the professionals of these devices and the network, as well as the surrounding community, since the final objective of the therapeutic-occupational intervention is the social inclusion of the served public.

It is necessary that, when aiming at the social inclusion of people, there is necessarily the assumption of building the path together with them, as it is a complex process that is never finished. It is necessary to monitor the person who lives in an SRT continuously, from the understanding that the autonomy and participation of these people in their daily lives is something to be encouraged, favored, experienced, and then conquered. Social inclusion is the result of this process.

The current level of commitment of a person, verified by professionals from different areas at the time of the assessment, in no way guarantees that their performance will remain unchanged for life. Therefore, the premise that, regardless of the observed limitations, the gaze of uncertainty about what is to come must never be abandoned should be part of the conduct and clinical reasoning of any professional dedicated to human life, since talking about participation is talk about desire, interest, history, relationships, memories and experiences that are in this other. Therefore, they are impossible to be analyzed so precisely and unaltered. Such conditions deal with the immateriality of the human being, which escapes the shackles of any pre-established assessment and any classification that assigns this person to an SRT, whether type I or II. This is because, even for those with greater need for help/supervision, the possibility of participating and exercising their autonomy must still be present. There is no deficiency, limitation or any other difficulty that justifies forgetting these aspects or the impossibility of stimulating them, according to the subject's ability and interest.

We argue that these considerations are fundamental for any proposal to work with residents of therapeutic residential services that aim at social inclusion.

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