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Chronic mental disorders and palliative care: the practice of occupational therapists

Transtornos mentais crônicos e cuidados paliativos: a prática de terapeutas Ocupacionais

Trastornos mentales crónicos y cuidados paliativos: la práctica de terapeutas ocupacionales

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This study investigated the practice of occupational therapists, as well as their approaches and resources used in mental health, from the perspective of palliative care. This study is a qualitative, exploratory and descriptive research, conducted in the second term of 2019 in Belém, in the state of Pará, Brazil. Data collection was performed through semi-directed interviews and, for analysis, through Bardin's content analysis. The participants were four occupational therapists working in a psychiatric emergency referral hospital. Four categories emerged 1) *Relationship between palliative care approach and mental health*; 2) *Practice of occupational therapists working in mental health using palliative care approach*; 3) *Resources used by occupational therapists in their practices in the context of mental health*; 4) *Challenges encountered by occupational therapists when working with the palliative care approach in mental health*. The professionals interviewed already used palliative care approach in their practices in the field of mental health, having several resources to offer an increase in the quality of life of their clients. There was a lack of studies on the theme in the specificity of the field of Occupational Therapy.
Descriptors: Mental health; Mental disorders; Palliative care; Occupational therapy.

O objetivo desse estudo foi investigar a prática de terapeutas ocupacionais, bem como suas abordagens e recursos utilizados na saúde mental, a partir da perspectiva dos cuidados paliativos. Esta é uma pesquisa qualitativa, de caráter exploratório e descritivo, realizada no segundo semestre de 2019 em Belém do Pará, Pará. A coleta de dados foi realizada por meio de entrevista semidirigida e, para a análise, utilizou-se análise de conteúdo de Bardin. Participaram quatro terapeutas ocupacionais atuantes em um hospital de referência em emergência psiquiátrica. Emergiram quatro categorias: 1) *Relação entre a abordagem dos cuidados paliativos e saúde mental; 2) Prática do terapeuta ocupacional atuante em saúde mental utilizando a abordagem dos cuidados paliativos; 3) Recursos utilizados por terapeutas ocupacionais em suas práticas no contexto da saúde mental; 4) Desafios encontrados pelo terapeuta ocupacional ao trabalhar com a abordagem dos cuidados paliativos na saúde mental*. Os profissionais entrevistados já utilizavam em suas práticas no campo da Saúde Mental a abordagem dos cuidados paliativos, dispondo de diversos recursos em busca de oferecer a ampliação da qualidade de vida de seus clientes. Percebeu-se escassez de estudos sobre a temática na especificidade do campo da Terapia Ocupacional.
Descritores: Saúde mental; Transtornos mentais; Cuidados paliativos; Terapia ocupacional.

El objetivo de este estudio fue investigar la práctica de los terapeutas ocupacionales, así como sus enfoques y recursos utilizados en salud mental, desde la perspectiva de los cuidados paliativos. Esta es una investigación cualitativa, de carácter exploratorio y descriptivo, realizada en el segundo semestre de 2019 en Belém do Pará, Pará, Brasil. La recogida de datos se realizó mediante entrevistas semidirigida y, para el análisis, se utilizó el análisis de contenido de Bardin. Participaron cuatro terapeutas ocupacionales que trabajan en un hospital de referencia en urgencias psiquiátricas. Surgieron cuatro categorías: *1) Relación entre el enfoque de cuidados paliativos y la salud mental; 2) Práctica del terapeuta ocupacional actuando en salud mental utilizando el enfoque de cuidados paliativos; 3) Recursos utilizados por los terapeutas ocupacionales en su práctica en el contexto de la salud mental; 4) Desafíos enfrentados por el terapeuta ocupacional cuando trabaja con el enfoque de cuidados paliativos en salud mental*. Los profesionales entrevistados ya utilizaban en sus prácticas en el ámbito de la Salud Mental el enfoque de los cuidados paliativos, haciendo uso de diversos recursos para ofrecer un aumento de la calidad de vida de sus clientes. Se observó una escasez de estudios sobre el tema en la especificidad del campo de la Terapia Ocupacional.
Descriptores: Salud mental; Transtornos mentales; Cuidados paliativos; Terapia ocupacional.

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INTRODUTION

The mental health field has been in a constant process of change in Brazil since the psychiatric reform, reflecting significant changes in the Brazilian psychosocial care network.

Over the last 20 years, changes have been occurring to respond to the demands of the Psychosocial Care Network (PCN), and the type of asylum treatment that had been provided to individuals with mental disorders was broken. In Brazil, those named "crazy," excluded from society, committed to asylums, mental hospitals or other types of psychiatric institutions, where they remained for a long period in a precarious situation, suffering daily physical and psychological violence from doctors, nurses and from other patients[1].

With the prohibition of psychiatric hospitalization in institutions with asylum characteristics, care devices were created in the territory, such as Psychosocial Care Centers (*Centros de Atenção Psicossocial* - CAPS), Therapeutic residences (TR), Coexistence Centers (*Centros de Coexistência* - CECOs), among others[2]. However, such services acted in isolation and not as a network. Thus, in December 2011, with its last review published in 2013, the Brazilian Ministry of Health established, in accordance with Ordinance No. 3,088, PCN as a network aimed at people with suffering or mental disorder and with needs arising from abusive use crack, alcohol and other drugs, within the scope of the Unified Health System (SUS)[3].

PCN is composed of a set of articulated actions and services, which ensure comprehensive mental health care[4]. Additionally It has the following composition: Primary Health Care, Specialized Psychosocial Care, Urgent and Emergency Care, Transitional Residential Care, Hospital Care, Deinstitutionalization and Psychosocial Rehabilitation Strategies[4]. In these, various points of care that substitute the asylum model are integrated, such as CAPS, CECOs, Family Health Units (FHU), RT, and comprehensive care beds in general hospitals[4,5].

Although there have been advances in policies for the care of people in psychological distress, there are still great challenges to be achieved in the field of mental health[6]. One of them is specifically related to the conceptions and expectations about the cure of mental disorders, added to the lack of adherence to pharmacological and/or non-pharmacological treatment, regardless of the reasons, by a significant portion of subjects with mental disorders, which tend to cooperate for a chronic condition of the disorder and/or for establishing frequent relapses[5].

Without consonant treatment, the psychiatric condition becomes more complex, configuring itself in a progressive worsening of symptoms, and it becomes a serious condition, from a functional point of view[6], and when there is a chronicity of the mental disorder, the possibilities of an expectation of improvement and expansion of the quality of life are reduced.

In view of this reality, it is necessary to prioritize the control of symptoms that bring pain, suffering, discomfort, poor quality of life for these subjects. These principles are in the palliative care approach, although still little associated with mental health practice, but valid and of great importance.

Palliative care can be directed to that individual who has an advanced disease and no longer responds to pharmacological treatment, to provide greater physical, psychological, social and spiritual comfort, alleviating suffering and improving the quality of life of that individual and their family/caregivers in the best way possible[7]. This approach has been highlighted in the absence of more effective therapies, as it does not centrally combat a specific disease or condition, but rather to optimally manage the symptoms and disabilities that may present themselves[8].

When talking about palliative care in mental health, numerous issues immediately arise, since it is an underexplored context, being one of the major barriers encountered by the user who needs this care and their family/caregiver access to this service, chronic psychiatric condition already affected them and they live socially isolated, unable to seek the service

independently or their family/caregiver does not have correct guidance on the management of this care, or there is a situation of user does not have a family member or a caregiver who can seek the service for him[8].

The multi-professional team in palliative care is of paramount importance since the patient must be assisted comprehensively and is only possible when there is diverse knowledge working together, capable of building interventions aimed at contemplating physical, psychosocial and spiritual aspects of the patient and their families/caregivers[9].

As the occupational therapist is a professional who is a member of a multidisciplinary team, he or she plays an essential role, as their focus of analysis and intervention are the significant occupations for the client, including activities of daily living (ADL), instrumental activities of daily living (IADL) and leisure, evaluating how or what is the best resource to be used to reduce impacts of the state of illness on the occupational performance of this individual, and thus improve their quality of life, regardless of the stage of the mental disorder[10].

Different skills of the occupational therapist are possible when working together with individuals in palliative care: group interventions together with the family/caregiver, seeking to favor social participation, functionality, autonomy, interpersonal relationships, teaching energy conservation and non-pharmacological techniques for control symptoms[11], among others.

However, it is observed that few studies demonstrate the role of occupational therapists with users who are in palliative care due to mental disorders. Therefore, this article investigates the practice of occupational therapists, as well as their approaches and resources used in mental health from the perspective of palliative care.

METHODS

This study is a qualitative, exploratory and descriptive research. This type of approach was chosen to make it possible to analyze and interpret deep aspects of a given situation and describe the characteristics of a given population or phenomenon[12].

Data collection occurred with occupational therapists from the psychiatric clinic of a public hospital of reference in psychiatric emergency in a state capital in the Northern region of Brazil, from July to November 2019.

The inclusion criteria were being occupational therapists from hospital described above and that had their place of professional practice, who worked in mental health; accepted to participate in the research by signing the Informed Consent Form (ICF); and who acted within the perspective of palliative care. As an exclusion criterion: who worked only in management positions.

Data collection was performed using semi-structured interviews. The data collection instrument consisted of questions of social and professional characterization (name, gender, date of birth, data regarding professional training, among others) and a script of triggering questions about the practice of occupational therapists from the perspective of care palliative care in mental health, which contained the following questions: 1) Do you see any relationship between palliative care and mental health? Which? 2) What do you do in your professional practice that you consider palliative care? Give examples; 3) Which type(s) of resources do you most use to achieve your goals from the perspective of palliative care?; 4) What(s) the main challenge(s) do you face when working with palliative care in mental health?

There was only one meeting with each participant for data collection. The interviews occurred in moments of availability in their hours and in a physical work environment. The interviews lasted approximately 30 minutes, upon authorization, the answers were recorded in digital media, transcribed in full and later interpreted. The research participants, throughout the study, were identified with random fictitious proper names, to preserve identity secrecy and confidentiality, the recorded responses were eliminated after the process.

After the transcription and analysis of the data, clippings of the predominant excerpts were made. Afterwards, the speeches were divided into thematic categories, being analyzed through Bardin's discourse analysis[13].

A Microsoft Office Excel 2013 spreadsheet was produced with the collected social and professional data and the answers to the questions regarding the central idea of the research and the descriptions were synthesized in main excerpts so that the material could be explored.

Research Ethics Committee of the Universidade Federal do Pará approved this study (Opinion 3,373,813) and also the Research Ethics Committee of the hospital (Opinion 3,435,871). All respondents participated in the survey by signing the Informed Consent Form (ICF).

RESULTS

Four occupational therapists who worked in two sectors of the psychiatric clinic of the hospital from this research participated, the psychiatric emergency ward (*Ala de Emergência Psiquiátrica* - EMER) and the Brief Inpatient Section (*Setor de Internação Breve* - sib), which offers a comprehensive care through short hospitalizations. This sector has thirty beds, 15 for men and 15 for women. The largest number of participants in this study were Occupational Therapy residents at the institution, with an average of one year and six months in the service (Table 1).

Table 1. Occupational Therapists, Hospital... Belém do Pará, 2019.

Participant	Gender	Age	Training time	Time of professional experience	Sector
Luciano	M	41 years	17 years	12 years	SIB
Júlia	F	22 years	1 year	6 months	SIB
Ana	F	24 years	2 years	1 year	SIB
Renata	F	23 years	2 years	1 year and 6 months	EMER

From the analysis and interpretation of the statements and reports collected, four categories emerged 1) *Relationship between palliative care approach and mental health*; 2) *Practice of occupational therapists working in mental health using palliative care approach*; 3) *resources used by occupational therapists in their practices in the context of mental health*; 4) *Challenges encountered by occupational therapists when working with the palliative care approach in mental health*.

Relationship between palliative care approach and mental health

The chronicity process of the mental disorder was the justification given by some participants to relate the palliative care approach with mental health. They also stated that this process was responsible for the loss of basic functions of the user's daily life and their quality of life, as noted

Yes, I see this relationship. Here at the hospital, what we see are many chronically ill patients with a history of several hospitalizations, and we are increasingly observing a decline in these patients in relation to the functions they have in their daily lives [...] *it is clear , we observe mainly with patients with schizophrenia, for example, they end up showing a decline in their functions, as in their autonomy, their thoughts become much poorer, they have difficulty maintaining a dialog, in social interaction, if they have the feeling of indifference to each other.* [...] *they are increasingly losing their functions, and consequently, making the rehabilitation process more difficult.* (Luciano)

Most people who have mental disorders are in a chronic state, they will no longer evolve in relation to the clinical condition, so we must take care of this person palliatively, right? To promote a quality of life, I think this is clear, this relationship of care. (Ana)

After reflection by the interview, two participants reported that they could observe this professional relationship raised - mental health and palliative care:

Yes. When thinking that the approach to palliative care is not only when there patient's life expectancy is short, [...] *we see cases and cases that are serious that they will not get over of this condition, that the care will be focused at the end of life, I can see this relationship, yes, in more severe patients.* (Renata)

We have patients here who have already had some time, who have difficulty in encouraging them to do activities, encouraging interaction. So I have no knowledge on this subject. But I believe there is this interaction between palliative care and mental health. (Júlia)

Practice of occupational therapists working in mental health using palliative care approach

Respondents reported that just the fact of frequently offering intervention in the Occupational Therapy service to the patient, regardless of the degree of commitment and/or length of stay, was already considered a way of palliating in the context of mental health, as in Julia's speech:

What I do is not leaves patients who have been here for a long time without the work of the OT. The Occupational Therapy service always assisted them [...] *we search bring them to activities, bring them to external activities, manual activities, expressive activities.* (Júlia)

In the report of another professional, the importance of "*being a resource*" was highlighted, along with the humanization of care, focusing not only on symptom control, but on the need to listen to patients, and present a welcoming attitude toward them.:

I think that from the moment that we offer well-being, humanized care for these people, who are contained for several and several hours a day, and for several days due to chronicity, I believe that it is only because we dedicate ourselves so much, being interested in this patient, is already the differential in mental health, it is Occupational Therapy. (Renata)

It was also described working in the context of organizing the routine, stimulating the patient's daily autonomy, valuing, and personal rescue, all of which are considered palliative practices.

It was observed that the interviewees use several strategies from the palliative care approach, adapting them to the psychosocial context, thus presenting a range of possibilities for action, respecting the uniqueness of each client:

So, we can take more individual approaches and, through that, be encouraging these patients with their autonomy, also in relation to encouraging this part of self-care with them, due to the negligence they have, in relation to themselves, so we may be providing this aid, this autonomy. Examples will depend on each patient because we don't work with a recipe, we go through several activities, we try to be stimulating. (Luciano)

The activities of daily living are impaired, so we try encouraging brushing teeth, taking a shower, they are simple things, but for them, especially for the more chronically ill, it is difficult to take care of basic activities. So, for me, it's already a form of palliative care because it allows for quality of life. (Ana)

Resources used by occupational therapists in their practices in the context of mental health

It is focused on the creation of a therapeutic bond as the first and main resource to achieve the outlined proposals, making it possible, therefore, to think of different resources, activities and interventions for the client:

My main approach is the therapeutic bond, I think that above any activity or resource you must establish a bond with your patient, look for a relationship where they can feel at ease, they can feel good, being there, to that you can create a relationship of trust with your patient, so they will feel comfortable with you so that you can propose an approach, once that is done, then you will propose according to the patient's interests.

The activities of body language were brought by the participants as another resource used in practice:

I work a lot with the body, so normally, like most, they find it difficult to express themselves in words, so their body language is very important for us on the team. (Júlia)

I really like to use physical activities with the more chronically ill patients, because we realize that when they experience it in the body, they have more use. (Ana)

The preference for group activities and the importance of looking at what they call "*productive activities*" for this audience are also specified:

What I use the most are groups and activities with chronic patients, I use more expressive and productive [activities], *which can be with clay, posters, painting, dance, bodily and productive activities, which attract me a lot, with wooden sticks, handicrafts, because they see a final product, they see "wow, I can do this".* (Ana)

Some group interventions are presented as a direction to cognitive rehabilitation:

Cognitive rehabilitation activities are very important for this patient demand, for the time they spend here, so the orientation, time, space, are much more compromised than others who recently arrived. (Júlia)

There is a preference for playful interventions:

I like to use games a lot, [...] *playful activities, interaction, games, it depends a lot on the person's history* [...] *there was a patient that his entryway here was table games, it was dominoes, more fun activities, and that I really like to do, this is my activity profile, this is a resource I use with these patients who like playfulness to rescue their best, to minimize all these negative aspects what happens to hospitalization, because it's not easy to stay here, but to bring up something they have, plays, childhood, to bring of some leisure activity, social participation, I use games a lot.* (Renata)

Challenges encountered by occupational therapists when working with the palliative care approach in mental health

The difficulty in creating a therapeutic bond with the chronic patient is presented:

I believe that in this first moment, to have receptivity from the user, due to the chronic characteristics of the illness, is the biggest challenge, but that doesn't mean that it's impossible, with care, with patience, with humanized care, we can have access to this user. (Renata)

We have many challenges, but I think [...] *it is difficult to access them, difficult to create this bond, difficult for you to bring this patient, to make them interested, so that they have motivation because if we will remember of the occupation model, we do something because we are interested, we are motivated, we are active, we want to do something, it depends on this interest, this trust, this is the main challenge I think.* (Luciano)

Another point raised is the lack of norms that explain the practice of occupational therapists working in the context of mental health when using principles of palliative care approach in the care of their users. As a result, the multidisciplinary team face several barriers:

In my practice with patients, in my view, I am using palliative care approach, but there is nothing to validate this. Thus, this is not palliative care for the institution, so it has often happened here [in the hospital], *that I insist on a chronic patient and the person looks at me and* says *"he has been here for so long, and you're wasting time you could be investing in a young patient, who has a better prognosis," so I'm like, "guys, I'm an occupational therapist, I didn't have to invest precisely in the person who has no quality of life, who doesn't do you have a good prognosis?" so these institutional issues are big challenges.* (Ana)

DISCUSSION

In the work of Occupational Therapy at PCN, group interventions most commonly occur in three formats: therapeutic groups, therapeutic workshops and productive workshops. The groups are centered on established relationships, on the exchange of experiences and do not necessarily have the production of objects. The workshops use resources that enable the construction of a final product, and production mediates the relationships in the workshop. If the workshop proposal is linked to income generation, it becomes a productive workshop[14,15].

The importance of care was perceived, however, together, the difficulty in the interpersonal relationship between those who provide care emerges, with some dissonant attitudes in this palliative process.

The absence of norms that support the occupational therapist's practice in this context limit the intervention. A multi-professional team is needed, in which all professionals are mobilized and involved in the process of offering a better service to the client and their family. The improvement in the service involves being open to new approaches, improving what they already do and adopting a critical attitude, as long as it is constructive, in the care space of which they are a part.

When asked about the possible existence of a relationship between the palliative care approach and mental health, some occupational therapists participating in the study had difficulty in understanding it at first. However, when performing a self-reflection of their professional practices in question, responded positively, associating palliative practices with cases of severe mental disorder found in hospitals, without showing any expectation of improvement.

Conditions considered chronic in health consist of pathologies that demand continuous, long-term treatment, requiring permanent care[16], thus interfering with the individual's quality of life, which generates degrees of disability and limitation, especially motor and mental[17].

Individuals undergoing palliative care are experiencing daily losses. The occupational therapist promotes comfort, quality of life and help the client and caregiver about dealing with

the difficulties caused by functional, cognitive, social and emotional losses, as well as promoting autonomy and/or independence in occupational performance, through activities that report unique values and meanings for each subject[18].

Approaches and interventions that are performed with clients with mental disorders, through palliative forms, were described. Individual approaches, with the aim of encouraging autonomy, the organization of the routine, personal valuation, social relationship and DLA, are conducted with an emphasis on independence and self-care that is neglected, due to the symptoms of the mental disorder.

The direction of the occupational therapist in this context restructuring and expand the possibility of autonomy, the act of doing something, and the patient's decision-making, seeking not only the construction of new activities, but the permanence of those that have meaning, as well as the experience of power before the rescue of capacities[19].

Humanized care was a highlighted point, as the attitude of caring with scientific competence without, however, forgetting the value of the human being, in addition to the remaining empathetic toward the client and their life story. Such characteristics were considered inherent to palliative care, being prioritized in care.

It is the health professional's role to present good listening skills and to be sensitized to the demand brought by the user. Therefore, it is essential to know who is listening, how and about what is being said, recognizing the uniqueness of each client[20] and remaining open to the perception of feelings arising from both empathy and resistance.

The creation of the therapist-client bond was described as the first and main resource when thinking about an activity or therapeutic plan. It is after creating a bond and establishing a relationship of trust with the client that an occupational therapeutic intervention can be proposed, considering their interests and occupational history.

The bond is essential for adherence to the therapeutic process and, therefore, for the effectiveness and determination in the construction of health care, in general, and in the absence of it, one cannot access the real demands, needs and users' desires – generating the imminent risk of failure of their interventions[21].

Instability in creating a bond with the person with mental disorders, especially in the chronic phase, Occupational Therapy professionals considered as a difficult barrier to be overcome[22].

Difficulty in creating interest on behalf of the client in the proposed therapeutic interventions was specified. Studies bring that among the main factors causes of non-adherence to treatment in this context, issues are related to the mental disorder itself and its symptoms[23,24]. On the other hand, the professional's attitudes related to language, time taken for care, welcoming behavior during interventions, respect for the patients' verbalization and questions, and motivation to comply with therapy is considered facilitators for adherence[24].

Activities with body expression in the aforementioned research provide clients with exploration and contact with their own body, stimulate self-confidence, expand body language and interpersonal relationships through activities with musical games, dance, mime, body games, relaxation, among others[25]. The bodily experience brings greater knowledge about the functioning of the body itself and this body awareness resulting from the practices can help in the remission of some symptoms[25].

In addition to possible motor impairments, avoiding cognitive and sensory losses with this patient profile is important. The research in question suggests activities to promote cognitive stimuli that encompass memory training; emphasis on attention; concentration; using games, activities with words, orientation in time and space, making calendars, and others[26].

For sensory stimuli, it is suggested to promote pleasant stimuli from the analysis of each participant's life history using touches, multiple textures, aromas, flavors, music, etc. The author's indications converge with the speeches of the study participants who originated in this

article, when they mentioned the importance of cognitive stimulation in their occupational therapeutic practices through group approaches[26].

The performance of therapeutic activities, whether with expressive, playful, bodily or artisanal focus, help in the process of adaptation and elaboration of the losses in their different dimensions resulting from the evolution of the psychiatric condition[27], and these approaches are used, as they help in the construction and/or improved self-esteem of customers and positively impact their recovery.

It was possible to observe different principles that govern the palliative approach, such as: pain relief and other unpleasant symptoms; affirmation of life and consideration of death as a natural process of life itself; neither accelerating nor postponing death; offering a support system that enables the patient to live as actively as possible until the moment of death; and focus on improving the quality of life[28].

Some important principles were not verified, such as support and involvement of a multidisciplinary team, and family members, during the process of disease development and mourning. A possible justification is due to the multidisciplinary team not considering the patient with mental disorder able to be cared for through the palliative care approach. The support not offered to the patients' relatives, for the most part, is due to their absence in the researched care environment. The abandonment of patients with mental disorders by the family itself is frequent in the investigated reality.

The use of the palliative care approach in the context of mental health is a field of practice that is still little explored. Therefore, there are ample and still unknown ways of acting, and thus, a field of action with challenges to be overcome by occupational therapists.

CONCLUSION

The practice of palliative care in Brazil is expanding, and occupational therapists have a significant role in identifying needs and offering support to patients, especially those in an advanced stage of illness.

This investigation showed that occupational therapists interviewed already use the palliative care approach in their daily practices, in the mental health sectors they work at, making use of several resources to help their practice and offer a better quality of life for their clients.

Regarding limitations of the study, the scarcity of scientific evidence in terms of published and accessible research on the intervention of occupational therapists in mental health using the palliative care approach is highlighted, as well as the small sample size and a single hospital, it is not possible to generalize the professionals' view.

In turn, this study can contribute to the construction of knowledge and, especially, to detain the attention of managers and professionals on the need to approach palliative care for individuals with mental disorders, especially those who are already in the chronic phase of the condition, with highlight the practice of the occupational therapist. More qualitative and quantitative research in other locations is also suggested.

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CONTRIBUTIONS
Alice Araújo Silva contributed to the design, collection and analysis of data and writing. **Ingrid Bergma da Silva Oliveira** participated in the design and review. **Luísa Sousa Monteiro Oliveira** worked on the design and revision. **Kátia Maki Omura** collaborated in the design, guidance and revision.

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