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The relationship between mental health and palliative care: perceptions of occupational therapists on the psychosocial network assistance

A relação entre saúde mental e cuidados paliativos: percepções de terapeutas ocupacionais da rede psicossocial

La relación entre salud mental y cuidados paliativos: percepciones de terapeutas ocupacionales de la red psicosocial

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The aim of this study was to understand the view of occupational therapists working on the relation between mental health and palliative care. This is a descriptive and exploratory study with a qualitative approach, carried out with 18 occupational therapists working in the area of mental health. A questionnaire was applied to obtain demographic data associated with a semi-structured interview. The study occurred in centers of psychosocial care and in a public hospital in Northern Brazil. The content analysis guided the treatment of data. The occupational therapists have found relations between the attention in mental health and palliative care, not always with exactitude, and showed interest in learning more about the subject. On the other hand, the professionals who worked with children did not find these relations.

Descriptors: Palliative care; Mental disorders; Occupational therapy; Mental health services.

O objetivo do estudo foi compreender a relação que os terapeutas ocupacionais atuantes na área fazem entre saúde mental e cuidados paliativos. Esta é uma pesquisa descritiva e exploratória de abordagem qualitativa, realizada com 18 terapeutas ocupacionais com atuação na área de saúde mental. Foi aplicado questionário para obtenção de dados demográficos e coletadas entrevistas semiestruturadas. O estudo ocorreu em centros de atenção psicossocial e em um hospital público no Norte do Brasil. A análise de conteúdo conduziu o tratamento de dados. Os terapeutas ocupacionais relacionaram a atenção na saúde mental com os cuidados paliativos, porém não de forma estrita, e mostraram interesse em conhecer mais sobre o assunto. Por outro lado, os profissionais que atuavam com crianças não fizeram esta relação.

Descritores: Cuidados paliativos; Transtornos mentais; Terapia ocupacional; Serviços de saúde mental.

El objetivo del estudio fue comprender la relación que los terapeutas ocupacionales actuantes en el área hacen entre salud mental y cuidados paliativos. Esta es una investigación descriptiva y exploratoria de abordaje cualitativo, realizada con 18 terapeutas ocupacionales con actuación en el área de salud mental. Fue aplicado un cuestionario para la obtención de datos demográficos y fueron colectadas entrevistas semiestructuradas. El estudio ocurrió en un centro de atención psicosocial y en un hospital público en el Norte de Brasil. El análisis de contenido condujo el tratamiento de datos. Los terapeutas ocupacionales relacionaron la atención en la salud mental con los cuidados paliativos, sin embargo, no de forma estricta, y mostraron interés en conocer más sobre el asunto. Por otro lado, los profesionales que actuaban con niños no establecieron esta relación.

Descriptores: Cuidados paliativos; Transtornos mentales; Terapia ocupacional; Servicios de salud mental.

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INTRODUCTION

With the advances of the psychiatric reform, a new way of looking at mental health treatments stood out, once the models used in old psychiatric hospitals showed a significant objectification of the subjects. What can be observed is a breakthrough in the search for humanized treatment, seeking the reintegration of the individual in society[1]

It is known that one of the most important characteristics of certain mental disorders is that they are chronic, which reduces the possibility of healing and raises the discussion about the control of the symptoms, for the maintenance of the quality of life of the individuals[2].

An intervention that is not frequently associated, but is relevant, if the state of the chronic users in mental health was to be analyzed, is the palliative care. Its actions are important because it does not seek healing, but to offer the maximum possible comfort to the user, from the diagnosis to the last day of life[3].

Mental disorders are defined as syndromes characterized by a significant disturbance in cognition, emotional regulation, or in the behavior of an individual, which reflects a dysfunction in psychological, biological, or development processes associated with mental functioning[4]. Mental disorders are often associated with distress or disabilities that affect social, professional, or other important activities[2].

Mental suffering must be heavily studied, because it is a chronic process, and for this reason can lead to temporary or permanent disabilities, associated with expenses due to payments of social security benefits and the social cost in consequence of the loss of workforce[5]. Therefore, it is considered to be an important Public Health problem.

Mental disorders have, as main consequences, the clinical factors that result from their chronic and disabling nature, as is the case with schizophrenia, bipolar affective disorder and other psychiatric disorders that are among the most serious and debilitating. People with severe mental disorders face two problems: the symptoms, that interfere in autonomy, independence, and quality of life, and the whole issue of social stigma[4].

Health practice in the mental field does not explicitly prescribe palliative care, so the attention to the users is not named as such. However, several contemporary clinical approaches in mental health can be considered palliative, since they aim to reduce the symptoms of people who suffer from mental illness, instead of trying to reach the remission or modification of the disease. Thus, according to the definition of palliative care, many of the interventions in the mental health aim to promote the quality of life instead of provoking remission, and thus, can be considered palliative[6].

In addition, seeing the care in Mental Health as a field of interdisciplinary intervention, the assistance must seek the social inclusion of individuals, and the perspective of professionals who need to consider their needs, be they biological, social or economic, no longer having healing as the main goal of the assistance[7].

For this reason, the treatment in mental health should provide a new possibility to modify and qualify the conditions and ways of life, guided by the production and maintenance of health and not limited to the cure of diseases. This means understanding that life can be perceived, experienced, and lived in multiple ways. For this, it is necessary to look at the person in their various dimensions, their desires, values and decisions[8].

Observing the need for a comprehensive mental health care, palliative care offers an approach that is not based on the protocols, but rather on the principles. It does not apply only to the end of life process, but in any case, of a disease that threatens life. The care is recommended since the diagnosis, expanding the field of action[3].

The World Health Organization[9] defines palliative care as an approach that promotes the quality of life of people and their families through the prevention and relief of suffering by means of early identification and reduction of pain and physical, psychosocial, and spiritual problems. In addition, palliative care is based on the principles of affirming life and considering death as a natural process, not accelerating or delaying it. It offers support for people to live as actively as possible, providing help to the family at all stages and in their mourning process, and other situations.

Considering the occupational therapist who works in palliative care, this professional is required to have a comprehensive and integral perception of the user who needs such care and, generally, manifests debilitating and stressful symptoms, in addition to the discomforts and physical and psychosocial suffering. Such symptoms directly impact on the occupations, and thus, the occupational therapist has the role to facilitate the process of adaptation of the patient to face the disease and its chronic process, considering the current situation, their prognosis and future perspectives, while respecting the needs and especially the desires of those who are being cared for and the members of their families, drawing on realistic plans in search of the solution of problems and in the organization of daily routine[10].

Considering the characteristics of mental disorders and the proposal of palliative care as a form of intervention for these cases, including the humanized vision that occupational therapists should present to direct their interventions to the individuals with mental illnesses, this study aimed to understand the relationship that the occupational therapists working in the area perceive between mental health and palliative care.

METHOD

This is a descriptive and exploratory study, with a qualitative approach. The characteristics of a qualitative study are the location where the subject is observed, being this the natural and unchanged environment of the subject. Another feature is the use, as the main instrument of collection, the researcher senses. In addition, the qualitative method offers greater data accuracy, since the observation and listening of the interview can be verified in depth, leading the researcher to the essence of the theme being studied[11].

An exploratory research, by its turn, has as a goal the development of hypotheses, in addition to increasing the knowledge of the researcher within a particular environment in which they want to start a study of a fact or phenomenon, to subsequently carry out a more precise research, to modify and clarify concepts[12]. Thus, the present research addresses a very new subject as it seeks to relate the palliative care with mental health, since there are few published studies about these themes.

Data collection was performed in a public hospital that has psychiatric care services and in the public network of psychosocial care in the north of Brazil. The research was conducted from September to November 2017.

The inclusion criteria were: being an occupational therapist and working in mental health institutions in the municipality selected for the study. Only one Psychosocial Care Center (CAPS) in the Municipality was not included in the research since it did not have an occupational therapist during the time in which the research was carried out.

Subsequently, a questionnaire to obtain the demographic data and a semi-structured interview with a guide made by the researchers were applied. All these steps were carried out in a single meeting with the participants, in moments of availability during their working hours, and on the physical environment of the institutions in which they worked.

The guide was divided into two parts: the first consisted in the identification of the health care professional (name, gender, date of birth, data relating to education, among others), and the second consisted of questions about the theme of the study. Upon authorization, the responses were audio-recorded, transcribed, and interpreted. The participants were identified with random names to maintain the confidentiality of their identity, and the recorded responses were deleted after the process.

For the interpretation of the data, the content analysis process was used. It is defined as "a set of techniques of communication analyses", regardless of the type of communication, that is, any context of meanings from a sender to a receiver, controlled or not by them[13].

The content analysis is organized basically in three steps: pre-analysis, exploration of material, and treatment of results, inference and interpretation. The first step (pre-analysis) is selected by the organization based on the intuitions of the researchers and aims to develop primitive ideas by organizing them in a way to get a logical and appropriate sequence to carry out the analysis[13].

In this aspect, a worksheet in Microsoft Office Excel 2013 was made with the data collected. The worksheet contained the following data: age, sex, place of work, time working on the job, and time since graduation. The answers of the questions were also distributed in the sheet, after being transcribed from audio to text. The most important passages were summarized, leading to the exploration of the material.

For each result, categories were established by affinity for better reading and understanding of the results based on the application of the questionnaire and personal data.

The study was approved by the Research Ethics Committee of the University Hospital João de Barros Barreto of the Federal University of Pará (number 2.146.804) and by the Research Ethics Committee of the Public State Foundation Hospital das Clínicas Gaspar Vianna (number 2.242.675)

RESULTS

Eighteen occupational therapists who worked in the area of mental health participated in the study, 16 females and 2 males.

Most of the occupational therapists worked on the CAPS with an assistance focused on the adult population, making up a total of 11 professionals (58%). The average age of the participants was 39 years (±7.0). In relation to the time since graduation, variability in the sample was observed, as well as in regards to the length of time working in mental health, as in Table 1.

Table 1. Professional data of the participants by service. North of Brazil, 2017.

Number of participants	Workplace	Average Time of Professional activity*	Average Time of Educational Training
11	Adult CAPS	11.4 years	17.2 years
4	Hospitalization service	10.2 years	12 years
3	Children and Youth CAPS	12.6 years	20.3 years

When questioned about the relationship between palliative care and mental health, and what way they could do to address it, the interviewees saw this relationship, but not as strictly related to mental disorders. However, one of the participants in the study perceived this relationship from their professional practice, when he reported the chronic nature of the disorders found in the mental health, according to the report:

Of course, I realize it, yes. As I said, you know, they don't have the cure of the disease. 'Oh, he 'has' a mental disorder and got cured.' That doesn't happen. It will be palliative care. The symptoms that appear, you know, we work to reduce them and see how they adapt to the new position in which they find themselves. (Angela).

It stands out, among the professionals who worked in a hospital context, that another professional, considering the specific profile in relation to other contexts of mental healthcare, emphasized mainly the process of desinstitutionalization of the user and the promotion of autonomy in the performance of their work:

(...) when you have a chronic case, you won't necessarily treat thinking of a cure. (...) we have to focus not on the question of the disease itself, right? The patient, he already 'is' in a well-advanced stage, then you will be working in conditions that are possible, the issue of trying to deinstitutionalize them and to find what is possible, a house, any location that can welcome them and can give a new meaning to their lives (...). (Edson).

It was found that the participants who acted on the CAPS perceived not only the relationship between palliative care and mental health in users who have some mental disorder, but also related it to their working environment:

Totally. Because we have many patients here at CAPS that are schizophrenic patients who have recurrent depression. And these patients we have to treat with palliative care, because we know that they will not be able to be 'cured' and some of the symptoms are going to persist, right? And some of the symptoms are very debilitating. (Gloria).

A whole relationship. At CAPS, we work with users that have severe and persistent mental disorders, that is, the vast majority of them will never recover to one hundred percent or find a cure. They are diseases that unfortunately even today we do not have a cure for, we have control. Mental suffering is a suffering that ends up making everyone in need of special support, this is where I see Palliative Care come in. (Natália).

It was also observed that some professionals have associated palliative care with the process of terminality of life, because some users could find themselves in a terminal stage of some other disease, and therefore, they might suffer psychically going through this situation as noted in the speech bellow:

Yes, we know that when a person starts a palliative procedure this will lead to many problems concerning that person's mental health, and she will need it (palliative care) until she actually reaches the time of death. So, up until what point I can be promoting the quality of mental health of this person that is in a palliative procedure, a terminal life process(...). (Carla).

Without a doubt. Today, we can see that many people come during a process of mourning, they come to our psychiatric clinic, psychiatric emergency, so we always get to see this link with the specifics of what Occupational Therapy can offer. When the person who 'is' in the process of death is well prepared, when she understands what is going on in her life, she can live better, and living better she has a much more enjoyable death process, as much as possible". (Daniela).

Two other professionals said that they do not understand the relationship between palliative care and mental health:

Well, I was not able to find it. Within the CAPS I cannot find it. Because here we don't experience this, right? At CAPS we don't experience any kind of situation where the individual is on the verge of death, except in the case of attempted suicide, but even so it's mostly a space thing, the individual is not going to die for sure, or has a certain date, his body 'is' weakened. (Joana).

Look, I even think it's a little weird relating the two themes, because we don't have a way to measure it, especially considering reality involving children and young adults, primarily we work a lot here with children, the psychiatric illnesses don't cause other comorbidities that the palliative care could help. I can't think of a direct correlation with children's mental health specifically". (Laura).

Both professionals related the concept of Palliative Care to terminality of life, that is, to the process of death, making no relation with the chronic aspect of the mental disorder, mainly due to the fact that both work with children.

In this context, it was observed that, among the participants of the study, few professionals did not notice the relationship with their performance as occupational therapists in mental health.

DISCUSSION

The seven occupational therapists who cited the existence of the relationship, understand that mental disorders can cause large losses to the life of a user. It is possible to control the symptoms, but there is no possibility of a cure. Thus, this individual is eligible to receive the approach of palliative care.

Edson, who worked in a psychiatric hospital, perceived a relationship between palliative care and mental health in users with mental disorders. For him, individuals in a hospital often have irreversible symptoms, which reiterates the issue of chronicity. In these cases, the care needs to target quality of life, without focusing only on cure.

These participants recognized the need for palliative care in mental health since they understood the chronicity of mental disorders. Although the majority of the population knows the prognosis of mental disorders, there are those who may still doubt their chronic nature. Families of mental health service users have a hopeful discourse when questioned about the future. There is hope in science, in the discovery of a cure, or in pharmacological interventions that provide more comfort and improvement of symptoms.

If a user found a cure, he no longer would be dependent on drugs or maybe could become an active participant in the family and social context[14].

For this reason, it is important that health care professionals understand that providing unrealistic expectations for users with chronic diseases can worsen the situation between the sick person and the natural course of the disease. Thus, when the expectations of the treatment and the disease evolution are properly aligned, they can promote the appreciation of possible short-term goals, in addition to reducing the discomfort and improving the quality of life[15].

Stand out, in the speeches of Gloria and Natalia, the perception of this relationship between palliative care and mental health within their work and in the establishment of a relationship between them and their way of working with this audience. This becomes clear when thinking about the CAPS, a place where it is possible to find various types of users, where people with mental disorders whose symptoms are more mild can be found, as well as those whose symptoms can be extremely harmful to their lives.

However, the services of CAPS are intended for those individuals whose disorders are chronic, recurrent and harmful to their performance in activities of daily life, without distinction of degree of difficulty. In this way, the importance of recognizing palliative care as a form of intervention with this population stand out.

The speeches of Carla and Daniela showed they recognize the existence of the relationship between palliative care and mental health, but not directed to the care of users with mental disorders, but rather to the individuals who are going through a process of illness that will result in the termination of their life, and therefore, need more attention to their mental health. For them, palliative care in the field of mental health is directed at aiding the patient to understand the process of death and mourning, thus promoting the quality of life of this sick individual. In addition, Daniela relates the process of terminality of life with the public found in psychiatric emergency.

A study[16] on the rates of mortality in psychiatric patients found as a result the existence of a high mortality rate, pointing out that in most studies reviewed, despite different approaches and correlations, the mortality was higher than in the general population.

Studies carried out in periods of change in mental health policies of various countries suggest the need for specific care and for the creation of support services appropriate for the deinstitutionalized clients[5,6,15,17]. This indicates the need for health policies directed at the general health care of individuals with mental disorders, consequently providing improvements in their quality of life.

Such benefits were apparent in a study that revealed reports of nurses that showed that users with mental disorder hospitalized in mental health institutions had many difficulties in re-integrating into society and, thus, needed palliative care in the mental health facility in a particular moment[17].

However, they showed difficulties because the possibilities of providing palliative care within mental health facilities are limited. Many users with mental disorders are transferred to environments of physical care at the end of their lives. This not only harms the continuity of care, but is also problematic because the providers of physical care may be unable to or not want to deal with psychiatric patients. Thus, users may not receive palliative care. What would be the most opportune and adequate[17].

Joana and Laura could not see the relationship between palliative care and mental health. However, it is important to emphasize that both participants worked in a CAPS focused at Children and Youth care. For them it was difficult to see the relationship between the two areas, because, according to them, in the work with children and adolescents it is not possible to notice the risk to life, or the presence of comorbidities that cause a need for palliative care, except in cases of attempted suicide, and even so, death was not a certain outcome.

As in the case of the concept of palliative care, mental healthcare for children and adolescents has only recently been recognized as a public health issue by the Unified Health System (SUS). This is considered to be one of the main challenges for the Brazilian Psychiatric Reform[18].

Some studies show that a large part of the clientele that seek mental health services to children and youth are mostly male, their main complaint being the poor academic performance, followed by aggressive behavior and disobedience at home and school[15]. In this context, it may be that situations found among the children and young adults at CAPS seem to be less severe, and so, make it more difficult to find the relationship with palliative care.

However, the Network for Psychosocial Care (RAPS) shows that the children and young adult CAPS have as a priority the attention to people with severe and persistent suffering or mental disorders, aimed at teenagers and young people from 12 to 18 years of age[19].

It is necessary to take into account that health care should consider the biological, psychological and social dimensions of the patients, and the contexts in which they are inserted. Many physical symptoms have their origin in situations of psychological distress in diverse ways. In many cases, the use of alcohol and other drugs can be associated to attempts at managing suffering on one's own[20].

Therefore, it is possible to understand that even with the possibility of a clientele with apparently mild symptoms, all suffering leads to difficulties in the life of individuals, which may intensify in a phase of great development, as are childhood and adolescence, and the palliative care shows itself as a possible way for the treatment of this population.

Thus, regarding the perceptions of the relationship between palliative care and mental health, different opinions were observed as to the way in which this relationship takes place and whether it exists. Some occupational therapists have reported to see a connection between the two themes, associating it to users who are diagnosed with mental disorders.

In addition, discourses were found of participants that see such a relationship, but do not necessarily associate it to users with mental disorders, associating this relationship to the mental health of people who are receiving palliative care. Some of the occupational therapists said that they do not see the existence of such a relationship from their perspective about the topics.

CONCLUSION

In the face of new perspectives regarding a more humane mental health care, this study provides knowledge about palliative care as an intervention strategy for individuals who have chronic and debilitating mental suffering, regardless of the proximity of death.

It also sought to verify whether the occupational therapists working in mental health observe such a relationship and in what way they do it, and it was possible to see a satisfactory result among the participants of the study, since a number of participants, in addition to recognizing the palliative care without the requirement of a death process, also see it as a possible strategic action in the field of mental health.

A surprising and positive result was the fact that the search instigated, in some professionals, the need for self-perception regarding their professional actions and a willingness to update and further their knowledge, even instigating the need to acquire knowledge on how to perform and carry out palliative healthcare. It is interesting to imagine that if the application of an interview was able to awaken such feelings, more directional actions, like discussions and the dissemination of the theme should be able to significantly help the production of knowledge on the subject.

It is important to mention that this study has limitations related to the number of participants, since not all professionals of Occupational Therapy working in the municipality where the study was carried out were interviewed, it is not possible to generalize the perspective of the professionals about palliative care and mental health

Despite this, the present study will be able to collaborate to a greater dissemination of knowledge in the scientific community about how occupational therapists perceive palliative care and how they understand their professional practices within the context of mental health.

More research is required on the subject, whose discussion is still poorly disseminated, in order to expand the theoretical framework on the subject.

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CONTRIBUTIONS

Alanna Julie Leão Ferreira and **Fabiana Sousa Ribeiro** contributed in the design, data collection, analysis, interpretation, discussion, and writing. **Kátia Maki Omura** has served in guiding the theoretical and methodological framework of the research, analysis and discussion. **Victor Augusto Cavaleiro Correa** and **Luísa Sousa Monteiro Oliveira** assisted in the analysis, discussion and review.

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