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Experience Report

From the paralysis of everyday life: openning health spaces from the recognition of symptoms

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Abstract: We start from the idea that occupational therapy client/patient struggles to run their daily life for many and varied reasons. Illness may be one of many different reasons leading subjects to experience restriction in daily activities or a daily routine merely related to the treatment, resulting from the loss of self-control in the world brought about by the new established situation. This paper presents a clinical case of a young woman with a diagnostic hypothesis of bipolar affective disorder and discusses how the non-recognition and unfamiliarity with the new contour arising from the illness open space for occupational therapy care. Moreover, we try to elucidate elements of clinical reasoning and procedures used by a student of occupational therapy during his fieldwork education on mental health. Our reflections are based on the Dynamics Occupational Therapy Method (DOTM) whose proposal is to extend health spaces into the client/patient's life so as to build/expand their daily life activities, based on the analysis of the triadic relationship dynamic (occupational therapist, subject and activities). This experience report is composed by the situational diagnosis of the case, the development of the therapeutic process and the reflections and analysis that the case raised during the fieldwork experience in occupational therapy in mental health.

Keywords: *Occupational Therapy/Method, Occupational Therapy/Therapeutics, Mental Health, Mental Disorders, Health Knowledge, Attitudes, Practice.*

Da paralisia do cotidiano: abrindo espaços de saúde a partir do reconhecimento da doença

Resumo: Este trabalho parte da ideia de que o sujeito-alvo da terapia ocupacional é aquele com dificuldades em seu cotidiano por razões diversas e variadas. O adoecimento pode ser uma das razões que influenciam a vivência de um cotidiano restrito ou com atividades relacionadas apenas ao tratamento, decorrentes da perda de domínio de si, no mundo, pela nova situação instaurada. Este artigo pretende apresentar um caso clínico de uma jovem com hipótese diagnóstica de transtorno afetivo bipolar e discutir o quanto o não reconhecimento e a não familiaridade com o novo contorno, advindo pelo adoecimento, abrem espaço para o cuidado em terapia ocupacional. Além disso, busca-se elucidar elementos do raciocínio clínico e dos procedimentos utilizados por um estagiário de terapia ocupacional em saúde mental, para conduzir esse processo terapêutico. As reflexões deste trabalho sustentam-se no Método Terapia Ocupacional Dinâmica (MTOD), que propõe ampliar espaços de saúde para o sujeito-alvo, de modo a construir/ampliar seu cotidiano, a partir do seu núcleo central, que é a dinâmica da relação triádica (terapeuta ocupacional, sujeito e atividades). Este relato de experiência é constituído pelo diagnóstico situacional do caso, pelo desenvolvimento do processo terapêutico e pelas reflexões e análises que o caso suscitou durante o estágio profissional em terapia ocupacional em saúde mental.

Palavras-chave: *Terapia Ocupacional/Métodos, Terapia Ocupacional/Terapêutica, Saúde Mental, Transtornos Mentais, Conhecimentos, Atitudes e Práticas em Saúde.*

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1 Introduction

We start from the idea that the target individual of occupational therapy experiences situations that lead to loss of control over oneself in the world and to the consequent impossibility of projecting the future and projecting oneself into it (KUJAWSKI, 1991; FERRY, 2010), placing such individual in a *position of exclusion* and paralysis in daily life (BENETTON, 2006, 2010).

The everyday life embraces the individual in the plan of his life in common with others, as well as the expectations that are created in the relationship of people, one with each other and with things, functioning "[...] as an undeniable community grammar that we have to fill with our personal creativity" (KUJAWSKI, 1991, p. 35).

When everyday life goes into crisis, familiarity with what is around is lost, generating difficulties for self-recognition in this new context, as well as uneasiness and tension by being abruptly affected by what happens daily around us (KUJAWSKI, 1991).

The disease can be one of several reasons that cause individual to experience a restricted daily life or a life replete of activities related to treatment alone (TAKATORI, 2001), due to the new situation. Specifically, in the field of mental health:

> [...] it is in this scenario of loss of control over his/her life, his activities; of no longer recognizing oneself as before; the strangeness of what was once familiar; the naming of the disease as a shield for the establishment of interpersonal relations within a biomedical culture, that distances him/her from the construction of meanings about what has happened to him/her; from the uneasiness of the impossibility of tranquility due to the constant threat of the internal world, and sometimes of the external world; from the frequent lack of desire, that we are called to envisage possibilities of change for this personal and social reality (MARCOLINO, 2016).

Thus, the paradigm of treatment of diseases inherent in medical practice is in constant tension with occupational therapy, to the extent that the social value of the *absence of disease* is greater than that *one can live, even with the disease*, central to the paradigm of occupational therapy (BENETTON, 2005, 2010; MATTINGLY; FLEMING, 1994).

This experience report intends, in light of the discussion of a clinical case of a young woman with diagnostic hypothesis of bipolar affective disorder (BAD), to present the impact of the advent of a mental disorder in the daily life. It also aims to discuss how, at first, knowledge about the disease can be a strategy for recognition of the new contour, offering to illness a real place in the life of the person, in his relations with the social.

Our reflections are based on the Dynamic Occupational Therapy Method (DOTM) which proposes to expand health spaces for the target individual, in order to build/expand their daily life (BENETTON, 2010). Its central nucleus is the dynamics of the triadic relationship (occupational therapist, target individual and activities) and all the occupational therapist's procedures, which take into account the movements of action and reaction that are determinants of this particular dynamics of functioning (BENETTON; MARCOLINO, 2013).

Occupational therapy diagnostic in the MTOD is situational as describes points of interest related to the subject in the current situation of life at the beginning and during the therapeutic process, and the information obtained by the occupational therapist from what the subject talks about himself/herself and his/her activities, what he does in the *setting*, and what people around think about him/her (BENETTON, 2006).

In this sense, the objective of occupational therapy differs from the medical-clinical care, which is based on symptom healing/control; occupational therapy aims to strengthen self-knowledge and better ways of carrying out daily activities (BENETTON, 2005, 2010; BENETTON; MARCOLINO, 2013). Symptom is understood as a constituent of the individual and it is always seen in relation to the possibilities of expansion of activities for constructions in the daily life. Even care activities of the disease and/or symptoms can be glimpsed in the light of the expansion of healthy spaces (MAXIMINO et al., 2012).

2 Method

This is an experience report consisting in the situational diagnosis of the case, development of the therapeutic process and reflections and analyses that the case aroused. The reported case was followed during the first semester of 2014 in weekly - individual and group - sessions in a fieldwork education in occupational therapy in mental health, in a teaching-clinic.

As that is an educational, health care and research institution, all users of this service sign a Free and Informed Commitment Term, accepting their direct or indirect participation in studies, research

and scientific dissemination. All names used in this text are fictitious.

3 Experience Report

3.1 Situational diagnosis, based on the trainee-supervisors relationship

The information for the initial diagnostic composition was collected in the initial sessions, with emphasis on the impressions the trainee had of the first consultation, and in a consultation with the mother.

3.1.1 Forwarding

Michele is a young woman who was referred from the Occupational Therapy in Children and Adolescents' Mental Health sector to the Adult Mental Health with diagnosis of BAD, currently undergoing symptom remission, as she reached the age of 18 years and presents demands related to the adult world, such as desire to work.

BAD is a severe, chronic and recurrent disorder characterized by mood swings, and in which thoughts, emotions, and behavior change noticeably between episodes of euphoria and depression. It affects approximately 1.6% of the population and has a significant impact on the patient's life with possibility of causing significant functional impairment, inappropriate or unacceptable social behaviors and interpersonal relationship problems (MIASSO et al., 2009).

3.1.2 The first consultation, according to the trainee's report

At the first consultation, I noticed that Michele expressed shame, agitation and anxiety, visible in her "nervous laughter" and her "shrinking body" posture every time a question was directed to her. She said no longer having contact with friends, not leaving the house to go out and have fun, but staying home only, with her parents; she says to enjoy shopping at the supermarket with her father and going downtown to buy clothes with her mother, besides watching romantic movies and novels, listening to music and dancing in front of the radio at the living room, and doing some craft activities.

When asked why she was being followed up, she said a psychologist told her that would help her be less shy. She told me, embarrassed and apparently confused, who was also followed by the CAPS (Psychosocial Care Center) psychiatrist, for having a psychiatric condition, the BAD. She was silent shortly after saying this.

I noticed that Michele was slow to talk about it, her nervousness and body's restlessness were visible as we talked about the subject. My perception is that she referred to the diagnosis with great sorrow and sadness. After the brief silence, she said she agreed with the diagnosis because of the exacerbated mood swings, but added that she was not very knowledgeable about the condition, and was unable to say what exactly happened to her.

Then she said that even after the diagnosis, she went on with life. I told her that a few minutes ago she had said otherwise, that the activities and people in her life were limited to the house and parents. I asked her if she thought that having this problem was related to this present void of people and spaces. But she remained silent and thoughtful, with a posture in which her shoulders were slumped forward and her hands on her legs, but after a few seconds she said that the questioning corresponded to the reality she was experiencing.

To better understand her story and how her family members understood what had happened to her, I told her that I would need to talk to her family.

3.1.3 The advent of the disease and the crises

In the visit of the mother, she spoke of her distress in relation to her daughter's diagnosis, the doubts about the ability of her child to enter the job market, the fear of her future when the parents die and the fear that someone mess with her on the street or that she has a new psychiatric surge, in the absence of the parents.

The mother told me that, in times of crisis, which happened when the girl was between 14 and 16 years old, Michele would sit for a long time on the couch, staring at the floor. When she received a visit, she would hide in the bedroom and also spend a long time doing nothing, showing a loss of interest in doing the activities of daily life. She also told us about some episodes in which her daughter fantasizing about being pregnant with a prince. Nowadays, they report that the daughter continues as always, very shy and quiet, but that in the past she would be more lively about the day to day activities. The mother admitted that she and her husband adopted a overprotective attitude in relation to the child, but that they were willing to change.

3.1.4 School

According to Michele and her mother, she always had great grades and never had any learning problems, but since around the age of 12, they said that she did not want to go to school any more, which became even more evident during times of crisis, due to loss of interest, difficulty concentrating, and suicidal thinking. Despite this, she was able to resume school activities, sometimes doing them at home, sometimes at school, thus finishing High School.

3.1.5 Friendships

For the mother, Michele has always been quiet and shy and for this reason she believed that Michele had few friendships. Both Michele and her mother talked about Samanta as the closest friend, as they use to spend afternoons together in either Michele's or Samanta's house. After the crisis, a gap was set between the two. Both said that Samanta tried to contact Michele, but that Michele always found some excuse not to resume the friendship.

Michele said to have some remaining friendships from school time, but she admitted that it had been a long time since she does not see them. We noticed that Michele was ambivalent about the approximation of friends, including Samantha, sometimes showing overly confident and excited to resume friendships, but them sad, ashamed, guilty and with lack of will or pleasure, thus choosing to leave them aside and judging that it would be better to create new ties.

3.1.6 Relationship with the sister

Michele lives with her parents and her only older sister, Fabiana, and seems to admire her very much, always reporting situations related to her. Although she says that her relationship is good with all her relatives, she says she would like to talk more frequently with her sister. At times, Michele shows that she wants to be like Fabiana, to do activities like she does, such as traveling, having friends, dating and working, even in the same job. When she talks about these things, Michele seems to feel inferior to her sister.

3.1.7 The desire for the future

Michele has no professional background and experience, but has always shown a desire to work, to have a job, and she believed that earning her own money could help her be more independent. Despite of this, we observed that Michele presented difficulties in making decisions and taking initiatives in activities during occupational therapy, such as in the process of painting a vase, reported ahead. We believed that these difficulties could hinder her social participation and the desire to enter the labor world.

3.1.8 The dynamics of the triadic relationship

In the first sessions, the trainee maintained an investigative and questioning stance, which caused Michele to feel intimidated and more diffident. By modifying this way of putting himself in the relationship, being more relaxed and attentive to Michele's attitudes, gestures and actions, without worrying so much about what she said or answered, she was more willing to talk about herself and her life, spontaneously bringing out various subjects present in her daily life and becoming extremely willing to do activities and reflect on them.

3.1.9 Our initial hypothesis

Throughout the sessions, it was possible to understand that Michele's repertoire of friendships has been always restricted, that she has been rather an introspective and shy girl, but that she carried out her activities with autonomy and good performance. With the advent of the crisis, she and her family closed themselves in the unknown universe of the disease.

Moreover, the story of Michele's illness was not so clear, since the symptoms described by the family did not seem to fit BAD, which made it difficult to understand what had actually occurred. So, that was a first goal of occupational therapy: approaching the disease with Michele, so that we could understand the story, the context of its development, and what meanings she had attributed to what happened to her.

We realized that Michele was ashamed of having a psychiatric illness and of the behaviors she had in the crisis, although we did not know exactly how she understood what had happened to her, besides she being afraid that everything would happen again. This new universe seemed to be a major obstacle, not only for Michele, but also for her family, paralyzing them in the face of this new outlining, still unknown.

However, Michele did not seem to be a girl with no desire to move on, because she talked about projects, she reflected on her sister, she seemed to want to find something inside her to give her strength to do

what she would like to do, although in a stereotyped way, with all the excitement of meeting old friends, reliving memories of the past school, when she said that her social isolation did not exist.

Another important point was to acknowledge the openness of the family to review their attitudes toward Michele and work with us.

3.2 Therapeutic process in light of DOTM assumptions

It is in the process of carrying out activities with the occupational therapist that the target individual will begin to give meaning to their experiences, consisting in a space of historicity and building a healthy daily life (in their own way), and enhancing social participation/insertion, which is the ultimate goal of the occupational therapy intervention (BENETTON, 2010).

Since daily life itself is embedded in the social context, as personal construction in social practice, occupational therapy in the DOTM proposes to be a meeting-building space to bring about transformations (BENETTON, 2010). In this sense, the therapeutic function is grounded on the educational action that, through learning, teaching and performing activities, allows the recognition of what belongs to the target individual, their real capacities, abilities and difficulties, opening space for the desire to do activities, which can be extended to everyday life (BENETTON, 2010; BENETTON; MARCOLINO, 2013).

With this structure for construction of clinical reasoning in a teaching and learning process of the practice, and with the initial diagnostic composition, it was possible to trace a therapeutic project for Michele. This foresees a change in her stance on the activities that she wished to make in her life and lessen the "size" of the unknown disease in her daily life. It is worth mentioning that this was a project developed by the trainee in question. As trainees change every six months, situational diagnoses and therapeutic projects are constantly produced, which is interesting given the constant change of the needs of people under our care.

3.2.1 Details of the process according to the trainee

At the session where Michele had begun to paint a ceramic vase, I pointed out that she had adopted a very passive posture, always waiting for me to make the choices for the realization of the activity and indicate the steps to be followed.

Although she did not say anything at the time, it was the beginning of our way of working, of putting the triadic relationship in motion. In later consultations, it was possible to see a change in her stance in relation to the activity, becoming more independent and spontaneous. Furthermore, I told her I realized she was not attentive to details that could leave her final product more interesting. I asked her if this stance could not be present in other activities of her daily life, seeking to open a space for her to think about what she has done and how she does the activities in life.

Michele has always been open to my observations. Most of the time, I would not build a dialogue in the here-and-now of the session, but I began to observe that she reflected on all the observations while outside the service and, in later moments, she tried a new way of being with me and performing the activities.

Given our hypothesis that the lack of knowledge about the disease kept the gap caused by what happened to her, I brought her some information about BAD.

This meeting was the "watershed" of this process, because Michele could identify herself with various symptoms of the disorder and we could reflect about what actions could be taken to ensure that the episodes became less frequent. It was possible to see that she felt very sad at every symptom she identified and very embarrassed when asked to report some experience related to the symptom. We believe that the manner in which she engaged in this activity helped her to speak of the disease and to relate it to events in her life, about which she had feelings shame and sadness. At the end of the session, I noticed she was strengthened, with some sense of control, which had been taken away.

After that, I proposed a meeting along with the mother so that the two could raise some problems that the advent of the disease, the overprotective relationship of the family and the passive attitude of Michele had caused. They reported the lack of initiative to carry out activities that she needed or wanted, the difficulty of accepting suggestions - leaving the family in a game of desire to stimulate her, followed by her rejecting that help, and they running out of energy to continue helping -, and her reactions, when having her wants thwarted, were some things that could be worked.

During the sessions, it was possible to observe that Michele managed to put into action a different

manner of being, making choices, justifying them, and taking control of what she wanted and was able to do, risking a little further.

In this trial, I helped her perceiving herself proactive, giving feedback to her achievements. We evaluated together how her activities were going in daily life. She started to come rather neat; by herself, taking the bus; she resumed contact with some friends by SMS; she began to go downtown alone to buy her things; started participating in an occupational therapy group with other young people at her age; she sought information on vocational courses; delivered curriculum in search for job; began to do craft activities in a school near her home; the fights with her parents became less frequent, which favored a closer relation and the accomplishment of activities with them and even with the sister.

Throughout this process, we worked hard: subject *of wishes and actions* × *subject arrested/paralyzed before the ignorance of the disease.* I sought to offer Michele numerous reflections, making her see her passive attitude. Also, with the course of the sessions, we saw a young woman experiencing a new way of being, doing and relating.

3.2.2 Evaluation of the therapeutic process through associative path

To the extent that the occupational therapist observes, collects information, he/she stays alert to possible associations during and while doing activities, working within a relationship that allows the construction of a story. This favors the chaining of ideas or achievements hitherto unnoticed by the subject, so that he may nominate and recognize acquisitions, skills, structures and self-knowledge, enriching his daily life (BENETTON, 2010).

Associative path represent a retrospective technique of analysis of activities with active participation of the patient/client in the process of grouping, comparing, and analyzing activities. It allows, therefore, a preferential construction of a narrative through what was done. This technique enables the construction of a subjective space of historicity that may tell not only the story of the patient/client out of the *setting* but also the story of the relationship built during the process of occupational therapy (BENETTON, 2005).

This whole process of enrichment of everyday life could be reflected along with Michele in the process of associative path by assessing all activities carried out until then.

Michele did not present difficulties when she was asked to separate the activities into groups, because she quickly put the easy activities in the group "*Easy*"; the activities that stimulated her imagination and helped her to understand her diagnosis, such as the script about bipolar affective disorder, in the group "*Good and Nice*"; the activities that caused her pain and sadness, such as when she had to list the symptoms she had already experienced and when she could not identify how the symptoms were interfering with her daily life, in the group named "*Difficult*".

In a second moment, after having had permission of Michele to modify the groups, the trainee maintained the activities within the group "*Easy*", but supplemented what these were easy because of the trainee's constant assistance and her passivity. A new group was set up to "*Watershed*", which was filled by the private consultation with the mother, since it was from that moment on that the parents gave spaces so that Michele could be "set free". The script about bipolar affective disorder was also placed in this group, because it helped her to know herself better and to realize that there is a disease, but this disease does not need to prevent her quality of life. Moreover, the trainee pointed out that, from that moment on, the bubble in which Michele was trapped exploded, and since then, she has been presenting herself with more self-esteem, initiative, autonomy, independence and social participation.

There was no change in the group named "*Difficult*", but the trainee pointed out that, despite the pains that these activities caused, they were also very important activities so that she could experience the change of attitude previously mentioned.

Michele chose not to modify the new distribution of the groups, because she argued that, in that way, she was better off, and she agreed with the notes made. In addition, Michele reported that she had not realized all this change, but that, after this process of associative path, she realized that she was acting really different. She said that she used to spend all day at home doing nothing, but today she is behaving different because she acts and goes to other places and activities. While Michele was speaking, it was possible to see that her eyes, mouth and body were smiling, light and content with this evolution.

4 Discussion

The disease discussed here in the light of a mental disorder brings contingencies for people's lives, causing them to experience most of their daily life

with activities related to the care of such disease (TAKATORI, 2001). Furthermore, the social impact of the advent of an illness or disability puts the person - and those who live with her - before conceptions/social representations of illness/disability that require an implicit decision about how to act, either by social isolation, denial, paralysis or confrontation. Most of the time, there is a paralysis of the life flow, which makes new health creations impossible (LIMA, 2006).

Thus, the attitude assumed by Michele's family is common due to the difficulties faced. Relatives of people with mental disorders do not know how to deal with situations of crisis. Because of this, family conflicts, guilt, pessimism, failure to see solutions to problems, social isolation, frustrated expectations of cure and lack of knowledge of the disease emerge (COLVERO et al., 2004).

In the movement between the individual and the social, this aspect seemed to be the fundamental target of our intervention. Thus, the care provided along with the family was centered in the daily life, in the analysis of activities that were necessary both for Michele's development - recalling that she experienced a mental health crisis in her adolescence and that much of what was worked with her is also part of the process of maturation itself - and for a positive affective and creative relationship in the family.

During the course of the visits, Michele allowed herself to experience a new way of being and doing, which was inaugurated when she was able to face/cope with what had happened to her, facing the symptoms of the disease and reflecting on the things she experienced when she was in crisis, taking ownership of this story. It was a difficult and painful process that allowed Michele to get to know herself better, to recognize something that is a part of her life, to open healthy spaces (mental health) to overcome her paralysis in the face of what had happened to her. As Solomon (2013, p. 26) says, treating the identity of the person as the disease "[...] invites the true disease to assume a more courageous stance".

It should be emphasized that our question was not about convicing on the existence of a disease or the attempt to fit personal experiences into symptoms. On the contrary, we believe that it is necessary to construct possibilities for subjects to call their experience as understanding or desiring, fomenting the idea of possession of that sense constructed in their daily life.

According to Lima (2006, p. 121), we are dealing with a practice linked to the idea of a quality and individualized life, in which

> [...] the biological fact cannot be thought of separately from cultural, historical, economic, and political data. This life, in its multiplicity, cannot be taken apart from the infinite ways of life.

By favoring the subject to acquire some mastery over the disease (even if this is of the possible knowledge), the occupational therapist can work to open spaces so that the mental health of subjects is triggered to think and to be able to experiment, and to carry out activities that favor their daily life, so that they be able to live life and not illness.

5 Conclusion

In the present case study sustained by the DOTM, we highlight aspects of a therapeutic process clarifying procedures that favor the diagnostic composition in occupational therapy, situational diagnosis in its qualitative analysis of all contexts relevant to the subject; and relational and educational procedures that, in the dynamics of a triadic relation, were composing a path, favoring self-knowledge as project to do and take ownership of activities of daily life.

The disease and its care are components of daily life and establish important relationships with the social context. In this report, activities related to the knowledge of the disease and their impact on family relationships and (restricted) activities were the ones that were most present. Thinking about social insertion and participation for the broadening of daily life implies interventions focused not only on the subject, but also on the people who participate in this daily life and who need to recognize the subject in his/her way of being, doing and relating.

Furthermore, we sought to demonstrate how it was possible through the associative path technique to evaluate the lived process and favor the target individual to build new senses from the analysis of the activities performed with the occupational therapist.

We hope that this work deepen the discussion about the diagnostic and procedural framework in occupational therapy, offer clinical evidence of the possibilities of structuring the clinical reasoning supported by the DOTM, including as experimentation in the fieldwork education (as in our case), and present a trigger for critical and reflexive processes on the possibilities of occupational therapy practice.

Acknowledgements

We thank Michele for her authorization to publish this report. At the time, while reading the manuscript with us almost a year later, she told us that she was even better than described in the text. Currently, she has been asked to leave the occupational therapy and has been followed in integrated activities of occupational therapy, psychology and psychiatry, in the same teaching-clinic, which has enabled us to take a more integrated care of her and her family.

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Author's Contributions

Guilherme Aguliari da Silva and Francine Baltazar Assad participated in the drafting, writing and discussion of the text. Taís Quevedo Marcolino participated in the conceptual review, discussion and final writing of the text. All authors approved the final version of the article.