REFACS

Therapeutic itineraries of family members in child and youth psychosocial care

Itinerários terapêuticos de familiares na atenção psicossocial infantojuvenil

Itinerarios terapéuticos de familiares en la atención psicosocial infantil y juvenil

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This is an exploratory descriptive study, with a qualitative approach, carried out in December 2017, in the Northern Region of the Distrito Federal, Brazil. It aimed to know the therapeutic itinerary of families and users of a Psychosocial Care Center for Children and Youth. Semi-structured and audio-recorded interviews were used and the data were subjected to thematic content analysis. Twelve family caregivers participated, mostly women. Two thematic categories and their subcategories were highlighted: *The informal system of care: family, alternative resources and community network* (*The context of family care*; *Search for support in alternative resources of the folk system and community network*), and *The formal system of care: intersectoral actions* (*School as a support network for the promotion and development of children and adolescents and expanded health care*; and *Psychosocial Care Network and the intersectoral network*). It was found in the *informal system*, a context of social vulnerability and resilience of family members, an initial tendency to seek spiritual support and challenges in the use of community resources for social inclusion. In the *formal system*, an arduous pilgrimage in services, fragmentation and intersectoral disarticulation and relevance of care at the Psychosocial Care Center. It points out the need for strengthening and articulating informal and formal systems, as well as professional training actions and expansion of the service network, to expand access and qualification of children's psychosocial care.
Descriptors: Health services accessibility; Comprehensive health care; Family; Mental health.

Trata-se de um estudo exploratório descritivo, de abordagem qualitativa, realizado em dezembro de 2017, na Região Norte do Distrito Federal, com o objetivo de conhecer o itinerário terapêutico de famílias e usuários de um Centro de Atenção Psicossocial Infantojuvenil. Utilizou-se entrevistas semiestruturadas e audiogravadas e os dados foram submetidos à análise de conteúdo temático. Participaram 12 familiares-cuidadores, na sua maioria mulheres. Foram evidenciadas duas categorias temáticas e suas subcategorias: *O sistema informal de cuidado: família, recursos alternativos e rede comunitária (O contexto de cuidado familiar*; *Busca de apoio em recursos alternativos do sistema folk e rede comunitária)*, e *O sistema formal de cuidado: ações intersetoriais (A escola como rede de apoio para a promoção e o desenvolvimento da criança e do adolescente e o cuidado ampliado em saúde*; e *Rede de Atenção Psicossocial e a rede intersetorial)*. Verificou-se no *sistema informal* um contexto de vulnerabilidade social e resiliência dos familiares, tendência inicial de busca de apoio espiritual e desafios na utilização dos recursos comunitários para inclusão social. No *sistema formal*, árdua peregrinação nos serviços, fragmentação e desarticulação intersetorial e relevância do atendimento no Centro de Atenção Psicossocial. Aponta-se a necessidade do fortalecimento e articulação dos sistemas informal e formal, bem como ações de capacitação profissional e expansão da rede de serviços, para ampliar o acesso e a qualificação da atenção psicossocial infantojuvenil.
Descritores: Acesso aos serviços de saúde; Assistência integral à saúde; Família; Saúde mental.

Se trata de un estudio exploratorio descriptivo, con enfoque cualitativo, realizado en diciembre de 2017, en la Región Norte del Distrito Federal, Brasil, con el objetivo de conocer el itinerario terapéutico de familias y usuarios de un Centro de Atención Psicosocial Infantil y Juvenil. Se utilizaron entrevistas semiestructuradas y grabadas en audio y los datos se sometieron a un análisis de contenido temático. Participaron 12 familiares-cuidadores, en su mayoría mujeres. Se evidenciaron dos categorías temáticas y sus subcategorías: *El sistema informal de cuidado: familia, recursos alternativos y red comunitaria (El contexto del cuidado familiar; Búsqueda de apoyo en recursos alternativos del sistema folk y red comunitaria)*, y *El sistema formal de cuidado: acciones intersectoriales (La escuela como red de apoyo a la promoción y desarrollo de los niños y adolescentes y el cuidado ampliado a salud; y Red de atención psicosocial y red intersectorial).* Se verificó en el *sistema informal* un contexto de vulnerabilidad social y resiliencia de los miembros de la familia, tendencia inicial a la búsqueda de apoyo espiritual y desafíos en el uso de recursos comunitarios para la inclusión social. En el *sistema formal*, arduo peregrinaje en los servicios, fragmentación y desarticulación intersectorial y relevancia de la atención en el Centro de Atención Psicosocial. Se señala la necesidad de fortalecer y articular los sistemas informal y formal, así como acciones de formación profesional y ampliación de la red de servicios, para ampliar el acceso y la cualificación de la atención psicosocial infantil y juvenil.
Descriptores: Accesibilidad a los servicios de salud; Atención integral de salud; Familia; Salud mental.

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INTRODUCTION

The model of mental health care for children and adolescents was highlighted in Brazil only in the mid-1980s, with the emergence of movements for redemocratization, promotion and defense of rights that constitutionally instituted children, adolescents and family as subjects, protagonists and citizens of rights, establishing policies of full protection, culminating, in 1990, in the publication of the *Estatuto da Criança e do Adolescente - ECA* (Statute of the Child and Adolescent)[1].

In this scenario, health responsibilities were given to children, adolescents and their families, with the establishment of attributions for all spheres of management regarding the fulfillment of necessary strategies to guarantee rights of protection and the integrality of health care[2]. In this context, discussions were promoted on the need for care spaces, which resulted in the development of a *Saúde Mental para Crianças e Adolescentes* - SMCA (Mental Health Policy for Children and Adolescents) in Brazil, contemplated in Ordinance GM No. 3088, of 2011, of the Ministry of Health, which established the Psychosocial Care Network (PCN)[1,3].

This ordinance adopts *Centro de Atenção Psicossocial* - CAPS (Psychosocial Care Center) as main components and articulators of health actions, including *CAPS Infantojuvenil* - CAPSi (Chil and Youth Psychosocial Care Center), responsible for caring for children and adolescents in intense psychological distress and dependence on alcohol and other drugs, enabling the directing of the organization of continued and expanded care network in each territory covered, based on intersectoral articulation[2].

The creation of a specific network for the mental health care of the child-juvenile population has been criticized, either for being numerically insufficient or for lack of specialized professionals. Such criticisms point to the need for reorientation of mental health services, including the optimization of existing resources, the strengthening of primary care and actions to promote the mental health of children and adolescents[4].

Studies on access to health services, especially on the prevalence of mental disorders, allow for an understanding of the barriers faced by users in seeking care, highlighting the unequal distribution of health services and the difficulties faced by existing services regarding the training of professionals and the resoluteness of actions in the face of high demand from users[1].

The overall prevalence of mental disorders in childhood and adolescence is 13.4%, with anxiety disorders being the most common (6.5%)[5]. A cohort study carried out in Brazil found a prevalence of 13.2% of diagnoses of mental disorders starting in adolescence, with 15.6% among boys and 10.7% among girls[6]. The analysis of epidemiological data corroborates the high demand for components of the children and youth PCN and the need to expand actions aimed at this group[5].

The need to expand the network is a fact, but next to this purpose, thre is ess need to develop studies that can highlight the strengths and weaknesses in territories where the line of care for children and adolescents is established. In order for services to attend to the population in a thorough and resoluteway, it is essential to highlight situations encountered daily by child and adolescent users and their families, especially in the difficulties of access and the path they must take until they are able to be assisted by specific mental health services and by other points in the network converging with the community-based psychosocial approach.

Psychosocial care within the territory consists of intersectoral services that need to work in an articulated, territorialized and transversal way, enabling an expanded clinic that does not reproduce stigmatizing practices related to mental disorders[7].

The therapeutic itinerary allows us to understand the various care logics and management practices by presenting the path taken by people and their families in search of care. In addition, it enables the formulation of effective care strategies based on the reality of users and their families, which can guide professionals working in mental health with guidelines for the implementation of more appropriate and effective actions[8,9]. Thus, this study

aims to understand the therapeutic itinerary of families and users of a Psychosocial Care Center for Children and Youth.

METHODS

This is an exploratory descriptive study, with a qualitative approach, which adopts the theoretical framework called "*Health Care System*", by Arthur Kleinman, one of the main ones on therapeutic itinerary for articulating different elements related to health, such as biological, physiological, symbolic and psychological realities and external influences, to offer explanations about disease and treatment, involving interpersonal relationships, experience of symptoms, decisions regarding treatment, therapeutic practices and evaluation of results[10].

This framework is composed of systems that cover sectors of care practices that are interrelated. The popular system, which corresponds to popular culture and common sense, in which diseases are initially identified and faced with the first decisions and actions taken, starting the therapeutic process that includes the individual; the family; the social network; members of the nearby community, as well as the formal system[10].

This system is closely linked to the folk system, composed of non-professional and non-legally recognized healing specialists who use alternative mystical and religious practices, such as spiritual surgeries, manipulative treatments, special exercises and healing rituals. Such care systems are characterized as informal. The formal system includes the propositions of care practices organized by legally recognized professionals, with formal learning and systematic records[10].

Data collection took place through semi-structured interviews with family members acting as caregivers and representatives of children/adolescents undergoing treatment at a CAPSi, in the Northern region of the Distrito Federal, in December 2017. The interview script had as trigger question: *Could you tell me about your experience from the moment you realized your family member needed help until they arrived at the CAPSi?* During the interviews, questions about the dynamics of the family and social context and the itinerary of each family until accessing and arriving at the CAPSi were explored.

The inclusion criterion for the participants was that the children/adolescents had been attending the service for at least one month. Participants were invited when they were attending to meetings and/or parent groups. The CAPSi management and the superintendence of the respective health region agreed. The criteria used to close the interviews followed the principle and strategy of theoretical saturation.

Data analysis and interpretation were submitted to the thematic content analysis method proposed by Bardin, based on the identification of the main emerging meanings[11].

This study is an excerpt from the research "*Reorganização dos e nos processos de trabalho na Rede de Atenção Psicossocial mediada pela avaliação participativa*" (Reorganization of and in work processes in the Psychosocial Care Network mediated by participatory assessment), carried out by the Observatório de Saúde Mental – OBSAM, of the Núcle de Estudos em Saúde Pública – NESP, Universdade de Brasília – UnB , with the financial support of the Ministry of Health.

The project was approved by the Research Ethics Committees of the Faculdade de Ciências em Saúde at UnB, under opinion No. 2.200.022, and by the Foundation for Fundação de Ensino e Pesquisa em Ciências da Saúde – FEPECS, under Opinion No. 2.270.086. The Free and Informed Consent Form was signed by the participant after the researcher had read and answered any doubts, ensuring anonymity and confidentiality of the data.

RESULTS

Twelve family caregivers and/or representatives of children/adolescents participated, of which 83% were mothers and only 17% were fathers; 67% were single, 25% were married and 8% were divorced; 50% had completed secondary education, 34% had incomplete primary

education, 8% had complete primary education and 8% had incomplete secondary education; 67% reported having a family income of up to two minimum wages and 33% had a family income of over two minimum wages; 42% of the families were composed only of the family member interviewed, the child/adolescent using the CAPSi and their siblings, while 58% had another family member (spouse or some other type of kinship).

Two thematic categories were highlighted: *The informal system of care: family, alternative resources and community network*, and *The formal system of care: intersectoral actions*.

The informal system of care: family, alternative resources and community network

In this category, the dimensions of the context of the family member responsible for the care of the child/adolescent, their difficulties, social and economic vulnerabilities and challenges for processes of resilience were highlighted in the care of children and adolescents. There was a significant search for alternative healing systems, especially religious practices. The limits of the family context and the fragility in offering support in other points of the community network were also observed, which could contribute to opportunities for development and socialization of the child/adolescent.

It was considered as subcategories: *The context of family care*; *Search for support in alternative resources of the folk system and community network.*

- The context of family care

The family is characterized as an element of the informal care system, responsible for identifying difficulties throughout development, promoting socialization conditions and meeting the psychosocial demands of children/adolescents in their primary care.

Most participants identified early, on average at 3 years, that their children had different behaviors from other children, causing concern in the family and difficulties at school. Among the actions observed, excessive restlessness, sleep difficulties and developmental delay, which intensified throughout early childhood, highlighting the need to seek help at the beginning of schooling.

In this initial school phase, the participants were alerted by teachers and other education professionals about aggressive behavior, socialization and learning difficulties or crises episodes, and were instructed to seek specialized care:

Since she was 3 years old, she had different behaviors, right, from other children. She was always problematic, she was a lot of trouble at school [...]. (F1)

It was since she was 3 years old that I started to notice that she had something that would be abnormal right?! She messed with everything, she didn't keep still; she couldn't watch a movie; delayed learning; talked in a very childish way, delayed and her behavior was not good either. (F2)

As the one responsible for the child's behavior, the interviewed family members reported experiencing, in an ambivalent way, a perception that something was wrong, sometimes accompanied by a feeling of guilt, but also something that prompted them to seek for help. Thus, these family members began a process of coping, seeking help, care and even cure. In this path of experience, most of them highlighted the encouragement received from medical health professionals for adequate and continuous treatment of their children/adolescents:

I can say that I had phases, right. I had a period of denial, of questioning, so I questioned myself as a mother, that I had spoiled my son a lot for him to be that way, but then the doctors guided me an explainedeverything. Then over time I accepted it, I went in search of treatment, a follow-up. (F7)

In this context, family members revealed that, by accepting that their child had something different from other children/adolescents, they began to understand and accept their condition of mental illness. However, they found themselves alone in the face of demands arising from the situation experienced. At times, the non-acceptance of the child's condition accentuated conflicts and/or culminated in separation between spouses or partners, causing emotional distance between those involved. Such situations can be intensified when they also experience stigma and discrimination in the family and social context:

His father is indifferent. So much so that we were married, we were married for 22 years, then 5 years ago we separated, for his sake, because his father didn't accept him, treated him as if he were crazy. So that I never accepted that, to treat him differently from others. (F5)

Mainly in my family, she suffers prejudice. [...] My sister, a teacher, she knows that it wasn't contagious, and she still didn't want to leave her baby near her, because she thought the baby would catch her disease, but it is not contagious. That hurt me so much, I was so sad to see that, that she didn't even want me to touch them [...]. (F12)

In some reports, the child/adolescent is the only one in the family to present some kind of disorder, which made this condition something new, unknown and very strange to the family caregiver and other people in the family nucleus. On the other hand, in a specific case, the family member reports having another child with the same type of disorder; the child is also being treated at CAPSi:

[...] And then, talking about [child's name]*, we decided to talk about* [child's sibling]*, who is his younger brother who is about two years apart. So, talking about the younger brother who also had very similar symptoms: nervousness, agitation, speech difficulties... So we talked about the two children and we had the diagnosis of autism in both children.* (F7)

[...] As a mother, right, I have three children, none of the others have ever had any health problems, [...] we feel sad, right. But on the other hand, I try [...] to be happy in other things [...] He is not a healthy child, but he is there, he plays, he talks, he runs. [...] So, like, [...] I comfort myself on that, right. Because there are parents who have a child in a wheelchair, who cannot speak, who cannot walk. So it's much worse. (F6)

Family members expressed concern about not being able to provide the best care related to daily activities of children with specific mental health needs, given the access barriers encountered in seeking help in health services. In addition, another difficulty indicated by family members is related to the fact that other family members do not know or do not adopt the behaviors recommended by the CAPSi and that should be used in daily life, which makes it difficult to care at home:

My family struggles with it. The things I learn here, how to deal with him, it's hard for me to put them into practice at home. They even said that I should bring my family, but it's very difficult to bring my family, right? Everyone works, studies and lacks willingness, of course. So there are many people who say: "ah, the problem is that you don't correct them, you don't spank them, you don't do it, you're doing it wrong", but they have difficulty with it [...]. (F11)

The experience of caring for a child who has many psychosocial demands due to mental illness and continuous monitoring has generated an emotional and physical burden in some respondents and can be the cause of physical and mental illnesses. Some family members reported that they are also monitored by a psychologist, considering that they are of great help in the treatment of the child/adolescent.

In view of this demand for child care, responsible family members, in general, emphasized whether or not they were in the labor market, which compromises the composition of family income, increasing the burden of these people in the daily routine of caring for their children, in their involvement with activities or consultations in health services and demands related to domestic activities. In their speeches, difficulties regarding the formation of competences and social skills are evident in the face of their children's illness process.

In the speech of the family members, there are life stories marked by the daily struggle to care for the child, the difficult negotiation at work to participate in health care and the dedication that often involves prioritizing child care at the expense of their own own care and demands:

[...] So I leave work with a lot of difficulty, a lot of criticism even, I get my medical attestation because he has the right, [...] I have to take care of him, so I take my attestation to work and everything and explain it properly. Because I need to help him, even a little, but the little he can manage, it's important to help him, it's the only way. (F10)

Family members report finding difficulties in the daily care of the child or adolescent in the presence of more exacerbated behavioral changes, such as disobedience, extreme dependence, impulsiveness, nervousness, restlessness and/or psychomotor agitation, hallucinations, fears, suicidal ideations and outbreaks, sleeping difficulties, adult or sexualized behaviors, relationship difficulties and the absence of other family members to count on:

She is aggressive, she doesn't respect me [...]. At school, I complain every day. And the other hand, she is very afraid, she is not alone at home, she is very dependent, [...] she sees the devil, she sees many things. She even screams, freaks out, and she takes medication [...]. (F1)

I used to live with the guardianship council in my house saying that she was being treated badly, that her behavior was not normal. They didn't understand that behavior was one thing, on her part. [...] You can't show her adult stuff because she starts to think that it's natural for her age. So, that behavior of hers saying: "I kissed her on the mouth", [...] they thought that I was the one who taught her that. And she saw it on television. For example, she even said at school that there was a shooting at my house, [...] so I was in a very difficult situation, even my family knows. (F2)

Despite these difficulties, family members emphasized the importance of understanding the limits that illness implies in the development of the child/adolescent, and begin to respect the pace of development of their children, in order to encourage and recognize their potential, without making excessive demands. Participants said they remain hopeful and committed to seeking care and information about the illness, highlighting the importance of an effective psychosocial approach:

I want her to learn her way, you know? I'm not demanding it anymore, because there was a lot of pressure on the family. They don't understand [...] We cannot demand that from an ill child. (F2)

- Search for support in alternative resources of the folk system and community network

Family members pointed out that, initially, they sought alternative models of help for the child/adolescent, including mystical or spiritual help, especially religion, in different places of expression, such as temples and churches, and other means that could provide a magical-spiritual answer for the pain and uncertainty they were experiencing. This search for alternative systems was justified by finding help, strength, comfort, acceptance and hope through prayer. Family members consider that spiritual support is a resource to maintain emotional balance and help to better understand and manage the situation:

In fact, I've even got to seek spiritual help. I even went, like, to people who read cards, then they say that her issue is spiritual, that it was something done to her and such. So sometimes I believed it, but I also go to church, I go to evangelical church too. I'm Catholic, but I go to the Evangelical church. And there are also people who take her to the praying circle, to the church, to liberation, you know? (F1)

With regard to seeking support from religion, some family members highlighted the importance of not failing to seek out the health area to carry out a medical evaluation and adequate treatment, in a shared coexistence between the informal search system and the formal care sector:

I think religion helps you have the strength to fight, but it doesn't solve the child's problem. [...] When a person has a child with this type of issue, they have to seek medical help, because just praying doesn't solve anything. Because it's not the devil, it's nothing like that! (F2)

Difficulties were reported in seeking other points in the social network that offer alternatives, such as courses, sports or recreational and cultural activities, which could provide support and social support, and also help in the process of socialization and development of their child /adolescent. They have as a limit not having time to accompany them, due to the interest in not creating conflict at work and not having other people to help them with care. Thus, the child or adolescent is unable to participate more in recreational and cultural activities:

No. Because I don't have time. He even wants to, he asks [...], because if that were the case I had to stop working because of him. He really needs to exercise, but I can't miss it... and I don't have anyone to help me in this department, I have no one. (F10)

Even with the difficulties pointed out, some family members speak of the effort to seek vacancies and enroll their children in various projects, especially when they perceive their aptitude and interest in sports, cultural and other activities. They believe that such activities can help them to control their agitation and nervousness and to continue their children's socialization. Parents report a desire to involve them especially in sports activities:

[...] I'm trying to get her to do sports, because she likes it a lot. Then I really want to enroll her in swimming classes. It's because I work and I have this displacement problem, do you understand? (F2)

In the child/adolescent's socialization and bonding, some family members bring the difficulty of managing to expand circulation in social spaces, given their difficulty in interaction, or even the fear that noisy environments with many people may act as triggers for expression of excessive aggressiveness and agitation behaviors. In these situations, the participants illustrate that they are subject to manifestations of prejudice and stigmatization, seeing themselves emotionally embarrassed or overwhelmed due to people's misunderstanding and

judgment about the child's behavior, interpreted as a "tantrum" situation that must be punished:

He can't interact. People generally don't like his way, they don't understand either, he's kind of rejected in society. The only people who like him are usually people who already know him like that, who have seen other children with the same behavior, then they have a better maturity and then understand that it is not entirely his will to do things. (F8)

So there are ignorant people that, when he is in a moment of agitation, of nervousness, "ah, your son is very naughty", right? So, there are people who are already judging without giving us the opportunity to explain why he is agitated, why he is nervous, right. (F7)

The formal system of care: intersectoral actions

The formal care system includes the formal care practices, organized by professionals, predominantly in the context of this study the school and the health services that make up the Child-Adolescent Psychosocial Care Network. The role of the school as one of the main formal support elements is highlighted.

Family members significantly pointed out the long pilgrimage process, highlighting the weaknesses of primary, secondary and tertiary health care and the important role of social assistance. In contrast, they positively characterize the specialized mental health care offered by CAPSi.

In this category, two subcategories emerged: *School as a support network for the promotion and development of children and adolescents and expanded health care*; and *Psychosocial Care Network and the intersectoral network.*

- School as a support network for the promotion and development of children and adolescents and expanded health care

The school was considered an essential social resource for the process of growth and development of children and adolescents, in the cognitive processes of learning and social inclusion. However, the school was appointed as a training institution, which was unprepared for the inclusion of children and adolescents with disabilities and mental health needs.

Family members added that educators valued the child's unique and altered behavioral aspects in the initial stage of schooling and the need to seek evaluation by health experts. These unique behaviors are arguments for learning difficulties and lack of attention, responsible for failures, suspensions, relational difficulties with colleagues and professionals, as well as episodes of aggressive reaction.

In addition to the difficulties presented by the children in the first years of school, the parents also perceived the experience of bullying, prejudice and stigma among peers and teachers in the school context. This violence was attributed to the lack of preparation of teachers to promote more inclusive and appropriate educational actions for the development of children, increasing the difficulties in achieving appropriate school performance, as well as social and psychological suffering:

We pray like this, to God [...] so we can have the strength to fight together with the child, because we know that a child with a problem will be discriminated against in the classroom. If they don't go to a small classroom, they will. So, we have this strength, to ask the teacher to get a book to give her to study at home [...] but do you know what they say? That they do not have paper available at school to do even one activity with a child [...] Even at school she had two failures, [...] because she had no follow-up, it is very difficult for her to learn in a classroom with 30-something students and she was placed in this situation several times, because there is no medical report [...] requiring for a smaller classroom. [...] Children suffer a lot at school, in their own lives they are discriminated against. [...] You can go to school and see how it is. It's a lot of children in need and they don't get it. (F2)

Family members emphasized the right of children/adolescents to have a classroom with a small number of students and educational strategies to reduce prejudice and discrimination experienced in the school environment. However, they pointed out that the lack of medical report due to diagnostic inconclusiveness prevents the inclusion in actions of this nature, necessary to ensure the rights of the child/adolescent. Thus, equity in the schooling and socialization process is subject to the educator's working conditions.

It was stated that there is a lack of knowledge on the part of schools about the existence of CAPS services, and that guidance on the need to seek specialized care occurs in a non-

assertive and generic way. The ways to discover care in the health service network are the responsibility of the family itself:

Oh no, here at CAPS, I didn't even know it existed here, the school she is at now didn't say anything to me. (F4)

It was discussed that schools need to improve the organization and qualification of teachers to welcome and assist children/adolescents who have different needs for formal learning at school. According to them, it is also important that these professionals seek to know the points of support and health care and that greater dissemination of the work carried out and the address where this service can be found is carried out, which also serves as a guideline for the performance of the CAPS:

- Psychosocial Care Network and the intersectoral network

Participants reported that the search for care in the formal health network involved a journey considered complex and, for some, too long, between passages in various services and specialists until arrival at the CAPSi, with an average duration of three years; in one of the most extreme case, the elapsed time was 8 years. They make a negative criticism of care in the health network in general, but when they get access and care at the CAPSi, they highlight the differential of effective psychosocial care offered by that service.

Some reported that, even with all the complexity of the pilgrimage by different specialists and tests carried out until diagnosis, it was possible to refer primary care services, a process similar to those that started in outpatient and/or hospital networks, through which children/ teenagers passed first, as well as recommendation from other people who knew the work of the place. Three family members reported that they resorted to the Guardianship Council due to its role in protecting the fundamental rights of children and adolescents, including access to health care.

The itinerary of family members through health services in the search for health care, in general, began in primary care services, by making appointments with pediatricians, in specialized outpatient services, such as *Policlínicas e Centro de Orientação Médico Psicopedagógica* - COMPP (Polyclinics and Psycho-Pedagogical Medical Guidance Center), philanthropic psychological care, public or private hospital services, and tertiary care, including neurologists, speech therapists, psychiatrists and psychologists.

In this context of care, family members considered such services as ineffective and without institutional reference. Criticism emphatically permeated the quality of care provided by health professionals, the absence of qualified listening in mental health to identify their demands and the conduct of professionals, centered on diagnosis and isolated and inefficient medicalization, without properly guiding or directing the family, in addition to the lack of necessary referrals, given the flow of care in the health network and in PCN, for comprehensive care to children and adolescents in the psychosocial approach:

To treat a child like this, you have to have full follow-up, it's no use paying a neurologist or a psychiatrist. [...] My daughter took a long time to be seen [...] it delayed her life a lot [...] it is really difficult. In public schools, children suffer a lot, because I got this vacancy through the guardianship council, because she was already suffering. Our health system is very precarious. [...] Until I got here it took lot of time. That's why I say that the part of the government, of resources, was very bad. (F2)

Family members reported difficulties in gaining access to laboratory and imaging tests to complete diagnoses, as part of the therapeutic itinerary to assess mental distress. According to their narratives, when the child/adolescent received a diagnosis, it worked as a passport to more specific and specialized care. Therefore, they repeatedly brought out the importance of organizing a reference and counter-referral flow, with responsible referrals in the services of the Psychosocial Care Network, which would guarantee earlier care in situations of mental suffering for children and adolescents. Thus, considering the discontinuity and non-resolvability of care in the public health network, they ended up resorting to the private network to ensure care for their children, showing the non-longitudinality and non-resolvability of the mental health care network for children and adolescents:

[...] The appointment takes time, and the actual consultation takes I don't know how many months, and then there's a queue, so I think that took away even my serenity. Because I was already giving up, I was already doing my own accounting. Because as I raise a lot of children, my salary sometimes can't handle it, paying health insurance. But I was already wanting to fix my life by getting a health plan. Because I couldn't stand to see my daughter's suffering in the public health network anymore [...] They should do an assessment, this assessment should be forwarded directly. Be it for the Children's Hospital, be it for the CAPS, be it for the COMPP, be it for something else. [...] Because this is horrible. And it's a lot of suffering for the family. [...] So it's something like that when the doctor saw the problem, he already forwards it right away, you know? [...] A place that would immediately be able to treat the child [...]. (F2)
I felt a little lost after the diagnosis [...] I felt a lack of medical support [...] it's not just a diagnosis and sending me away, no [...] What can the State offer you? Mental health. But where do you look for this Mental Health? [...] So, they charged me a lot, but they also offered me little and I felt very pressured. (F7)

The negative experience of the therapeutic itinerary was transformed when families were able to access the CAPSi service. Thus, family members brought positive reports about the care provided by professionals and about the health practices adopted at the place. The functioning of the CAPSi open-door system was positively evaluated by family members, who stressed that they felt welcomed, were active listened to and got clear guidance from the institution's professionals, and were included and linked to specific family health actions and care.:

Of all the places I went, CAPS was the place I liked the most. Because they don't just accompany the child, they end up doing work with the family. Because it's not just the child who has difficulties, the family takes some of this diagnosis for themselves. [...] So, really, we find the right people in the right place. (F7)

Respondents also pointed out the group work in the modality of expressive craft and painting workshops, recreational and culinary activities, film sessions, sports practice in the CAPSi's own multi-sports court, psychological and psychiatric follow-up, among others. These activities were identified as powerful resources that promote the development of children and adolescents and their families, offering support and strategies on how to deal with their children's behavior, ensuring access to the service, as well as providing other resources necessary for health assessment.

According to the family members, the CAPSi helped them to clarify the child/adolescent's condition and to develop the best way to proceed in their situation, in addition to the fact that the service was a place where they could make appointments, obtain free medication and test requests with ease, unlike what happened in other points of the network. In general, they believed that the assistance provided at CAPSi has contributed to the satisfactory development of their children's behavior.

Regarding suggestions for improving the service at CAPSi, family members highlighted the need for the government to provide more resources and investments for the service, as well as hiring and allocating more professionals, structural improvements and creation of more services. Uniquely, a family member suggested a more individualized weekly care time; another suggested carrying out a continuous daily activity, in which parents can leave the child/adolescent while they work:

The government has to give more resources, got it? Thing they don't give to CAPS. [...] So, the professionals here, they do their best, but the government doesn't, you know? [...] Put more professionals to care for these children, because they have no idea of how they suffer. What they go through even before getting here, or if they manage to get here, which many cannot. (F2)

DISCUSSION

The logic of the therapeutic itinerary described by the family proves that the first ways of seeking and coping with mental health care take place in the family context, and that the trajectory of discovering the diagnosis, experience and search for treatment for mental health problems in the child/adolescent characterizes a difficult situation, exhausting and accompanied by sadness[12].

Participants in this study are part of social classes with social and economic vulnerabilities, which can increase exposure to risks produced by social exclusion, caused or accentuated by poverty, income inequalities, precarious social conditions, difficulty in accessing health and education. The fragility of care in the field of mental health further

exacerbates the vulnerability to which people are exposed, as psychological distress can produce financial and social impacts on families.

The emergence of the disordered condition in the child/adolescent can cause a rupture from the ideal of 'normality' and the presence of divergent behaviors, which can generate suffering and promote difficulties in family dynamics, given that each member has a specific way of dealing with the situation. The care of a child or adolescent with a mental disorder can produce an intense burden, compromising the caregiver's health and social life, as well as the relationship with other family members, leisure, financial availability, domestic routine and professional performance, among other aspects. In addition, children and adolescents are stigmatized by the very characteristics of their condition and end up being isolated from the social environment in which they live[13].

The inclusion of the family in mental health treatment is still characterized as a challenge; but at the same time necessary for the creation of more effective singular therapeutic projects, considering that the mental health care of the child/adolescent is not disconnected from the family members. Therefore, the family is an essential element in the care developed[14] and, therefore, it is important that it is welcomed, can participate in therapeutic groups and receive guidance on coping strategies for difficulties encountered in living with a child/adolescent with a mental disorder[15,16].

Regarding financial difficulties, in many cases, the need arises for the family member to abandon their external work to dedicate themselves exclusively to the sick child/adolescent[16]. Thus, the financial social benefit for the user, when present, becomes a facilitating factor for the care provided by the family[13].

In the search for alternative care resources, religion stands out, in which family members inform that in addition to attending, they also take children/adolescents to religious services. Events of this nature are considered to have a positive influence on the treatment of psychosocial conditions, as they assume a meaning and a complementary support role, and can be characterized as spaces for welcoming, creating bonds and social support[17]. In crisis situations, families feel helpless and tend to seek religious practices, seeking in spirituality the support that provides strength to continue their struggle[18].

Regarding the formation of community networks and the inclusion of the child/adolescent in other types of activities, it is emphasized that, in addition to specific mental health services, the creation of intersectoral networks aimed at care in the territory and the creation of bonds produces a expanded clinical perspective, centered on the mobilization of family and social environments, involving community networks, leisure spaces and popular knowledge[14]. The search for alternative resources, such as home care, religious practices and support from family and friends, is relevant for mental health care, especially when formal resources are insufficient. This highlights the importance of the sociocultural context in the trajectory performed by users and family members[8].

In the context of children and youth, in addition to building networks, it is necessary to approach the policies of community life and its services, from the inclusion of territorial resources of citizenship, such as social centers, sports, leisure activities, clubs, among others. Thus, children and adolescents are recognized and guaranteed other spaces of care and attention that help in promoting health, autonomy and social participation[14].

Therefore, it is important that families and professionals know the available community network, in order to expand strategies for sharing responsibilities and to integrate it as a strong element in helping the family to resolve difficulties[18].

In the formal network, the role of the school stands out, considered one of the responsible social actors and one of the main places of development of children/adolescents, it is up to her to monitor their growth process and biopsychosocial well-being. The school has a fundamental role in guaranteeing the right to education, in light of the paradigm of school and social inclusion, and must be able to welcome the student and their reality, despite the differences.

However, according to the family members' narrative, the school has been configured as a space of exclusion, due to the lack of preparation of educators in dealing with children and adolescents who present difficulties/specificities that are beyond the standard[19].

The main findings about the difficulties faced by teachers regarding the inclusion of children and adolescents with special needs in school involve aspects related to weaknesses in their education, as well as in the interaction with the students' families and with the network's health services[20].

Considering the relevance of the school environment as a development context and as a potential environment for actions to promote mental health and possibilities of intervention aimed at primary health prevention and development promotion, in line with the concepts of inclusive education, it stands out the importance of training professionals, in order to facilitate links with other sectors of the community and anticipate the process of solving situations adverse to the well-being of the child/adolescent and, consequently, of their family.

In general, children and adolescents who present difficulties related to mental health are identified in the school environment as 'problem students', characterized as undisciplined for not meeting school standards, being indiscriminately labeled and reduced to their condition, without considering impacting aspects of your life. Dealing with this problem requires specific actions, aimed at offering the necessary support to meet individual needs, enabling full development throughout the entire school trajectory, through "pedagogical resources, assistive technology, human resources and insertion in the ways and means of communication best suited to each student"[21:122].

In other formal points of care in the children's psychosocial network, the lack of articulation between services is addressed, as well as theoretical-practical divergences, which resulted in discrepant directions, resulting in a long pilgrimage[12].

In the absence of resoluteness in primary care services, the first to be sought in the formal system, family members show in their reports a biomedical rationality in the organization of work, in order to understand phenomena related to mental health. In addition, they also refer to the lack of training of professionals to provide adequate care for mental health demands.

There was an absence of a 'differentiated look' to identify issues pertaining to child and youth development, generating insecurity and lack of knowledge regarding the cases, and a recurring demand for referral to specialized services. The qualification of primary care professionals can be strengthened by matrix support/sharing strategies between the Family Health Strategy and mental health services, such as CAPSi. This can be made possible through the joint construction of therapeutic projects that provide greater security to primary care workers in the development of psychosocial interventions, positively impacting access and qualification of care[22].

The need to obtain a medical report describing the diagnosis, which may enable access to social services, according to family members, is paradoxical in these contexts of fragmented and punctual care. Generally, professionals establish a distant contact in the service, with imprecise answers and non-responsible referrals, prolonging the pilgrimage[12]. On the other hand, the medical diagnosis, if established in a hasty way or analyzed in isolation, can lead to a process of pathologization and stigmatization. Family members expressed that they expected more than a diagnosis. They require an adequate reception and follow-up.

The arduous pilgrimage in the search for care by responsible family members, associated with a real perception of the insufficiency of CAPSi and of professionals trained for child and adolescent mental health care, verified in the Federal District region, corroborates studies that consider access and service and also the overload of existing services, with long waiting lines[12,23].

Specifically with regard to CAPSi, the positive assessment of the service, made by family members, unlike the assessment of other services in the network, confirms its importance in the care setting for mental illness in children, in convergence with the fulfillment of its

objectives, which involve provide support to family members, prioritizing knowledge, strengths and individual needs[18].

Universal reception, a guideline that guides the actions of CAPS, determines that the doors of services must always be open to all those who arrive with some mental health need, and this need must be received, heard and answered. In this sense, interventions and initial strategies are proposed in the CAPS space itself, as well as carrying out actions of intersectoral articulation[2]. The CAPS team must know the possibilities that the territory provides for the development of the therapeutic project for children/adolescents, especially schools, places where they are more present and that enable their territorial insertion. Thus, the joint work of CAPSi with the school assumes great importance in the interventions to be developed[24].

It proved important to strengthen the articulation of mental health services with Primary Health Care (PHC) teams, considering that this level of care is the gateway to the Unified Health System. organizes the general flow of services offered by the Network, in order to improve the resoluteness of care actions and reduce unnecessary referrals, contributing to the increased adherence of users and families to treatment[22].

In this sense, the participants requested that child care be provided with greater support to the family, highlighting the need for training of professionals involved in other aspects of PCN, especially in PHC regarding active listening, comprehensive care, and practices of reception and the referral and counter-referral actions between the devices. The approach to children's mental health requires the articulation of psychosocial interventions, psychological support and medication, and therapeutic projects should fully contemplate these three dimensions[24].

The family inclusion in the therapy was a reinforced factor, and, for that, the Parent Group was created in the investigated CAPSi, a space for talking and sharing the anguish and suffering involved in coping with the child/adolescent's mental disorder. Groups of this nature are a space for mutual support that allows family members to find solutions through the exchange of experiences and knowledge[15].

The mental health care of the child-juvenile population requires investment in the constitution of a network of specific care, with the professionals being responsible for offering the necessary support and social and therapeutic support. In the narratives of the study's family members, the CAPSi is consolidated as a strategic device in the development of a qualified and humanized listening, in the confrontation of stigmas, in the search for improved quality of life and a emancipatory process, through an integral vision that enables full participation and community inclusion[2].

The importance of sectors linked to social assistance was also pointed out, such as the Guardianship Council, which is considered one of the gateways for children and their families in the child-juvenile psychosocial care network. In crisis and emergency situations, which require immediate action, the council can be activated, together with the Children's Prosecutor's Office, Reference Centers in Social Assistance and Specialized Reference Centers in Social Assistance, in order to guarantee the fulfillment of rights social activities of children and adolescents[25].

Collaboration between different services, characterized by interdisciplinary and multidisciplinary actions, is a potential solution, as it promotes the articulation between the different environments frequented by children and adolescents, such as school, family and leisure spaces, enabling the realization of monitoring and treatment in health in an integrated way[26].

The social rights of children and adolescents must be observed from the perspective of deinstitutionalization, in the search for greater protagonism and social participation, and the rehabilitation process means building real access to citizenship rights and their progressive exercise. This exercise is also made possible by guaranteeing a space for speech for children/adolescents, which must be legitimized and announced in various spaces and

institutions in the territory and in the social fabric. Therefore, the expansion of social participation is directly related to the strengthening of PCN[27].

CONCLUSION

From the therapeutic itinerary followed by family members and their children/adolescent users of a CAPSi in the Distrito Federal, in the search for health care, with regard to barriers of access and care and treatment in mental health, it was learned that almost all of them are women and mothers with high social vulnerability, who assume the role of main caregiver of their child/adolescent.

In informal care and in community networks, inserted in popular and folk subsystems, churches proved to be a relevant resource in the community support network for the social inclusion and protection of children/adolescents, as well as family members.

In the formal system, in the assessment of family members, the importance of including the child/adolescent in the school space and the performance of CAPSi as a differentiated service of the Psychosocial Care Network, in the provision of qualified, effective and resolute care to children and adolescents, extended to family members, although little known by the general population.

In view of the new political guidelines for mental health care, as of 2017, with centrality of investment for the hospital, outpatient and specialized teams, it is worth considering the very positive assessment made by the CAPSi during the study, to reaffirm the importance of investment government in expanding the number of this service as a care and territorial device.

In the therapeutic itineraries, gaps were identified for formal intersectoral articulations with other alternative devices, family members and professionals, so that they can advance in the organization of management and the work process. This requires, fundamentally, decision-making in health actions by professionals, from the perspective of the expanded clinic and the psychosocial context of users and families, in addition to acting more focused on children's mental health care.

As limitations of the study, it is observed that the results are restricted to the perceptions of family members and a specific territory, it is important to develop research with health professionals and specific studies for children and adolescents in other RAPS health devices. Also, to associate studies of therapeutic itineraries, researches with quantitative data that can scale other issues related to mental health and quality of life, as well as the result of care actions among the devices of the Psychosocial Care Network in the growth and development of this population.

On the other hand, this research evidenced the need to strengthen the articulation of the informal and formal systems, as well as to implement actions of professional training and expansion of the service network, especially the CAPSi, in order to expand the access and qualification of care child-juvenile psychosocial, which although the data here cannot be generalized, but possibly reflect the reality of other regions of the country.

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