Challenges of the family caring for a person with mental disorders

RESUMO | Objetivo: Verificar na literatura científica os desafios enfrentados por familiares no cuidado da pessoa com Transtorno Mental. Método: Trata-se de uma revisão integrativa. Realizou-se a busca por artigos; com delimitação nos últimos 5 anos (2015-2020); nos idiomas português, inglês e espanhol; disponíveis na íntegra. Nas seguintes plataformas de dados: DOAJ, LILACS, MEDLINE, SciELO, SCOPUS e Web of Science. Resultados: Os dados foram organizados e apresentados em figuras e tabelas. Dos 5740 estudos encontrados, 160 estava disponível na DOAJ, 123 na LILACS, 3056 na MEDLINE, 28 na SciELO, 834 na SCOPUS e 1539 na Web of Science. Contudo, após a leitura permaneceram apenas os que atendiam aos critérios para inclusão e exclusão descritos na metodologia, 9 estudos. Conclusão: Observa-se que as instituições não estão prontas para colocar pessoas com transtorno mental na rua, devolver para suas residências ou expor para residências terapêuticas, sem nenhum apoio da rede.
Descritores: Transtornos Mentais; Família; Cuidadores.

ABSTRACT | Objective: To check the scientific literature the challenges faced by family members in the care of people with Mental Disorders. Method: This is an integrative review. The search for articles was carried out; with delimitation in the last 5 years (2015-2020); in Portuguese, English and Spanish; available in full. On the following data platforms: DOAJ, LILACS, MEDLINE, SciELO, SCOPUS and Web of Science. Results: Data were organized and presented in figures and tables. Of the 5740 studies found, 160 were available from DOAJ, 123 from LILACS, 3056 from MEDLINE, 28 from SciELO, 834 from SCOPUS and 1539 from the Web of Science. However, after reading, only those who met the criteria for inclusion and exclusion described in the methodology remained, 9 studies. Conclusion: It is observed that institutions are not ready to put people with mental disorders on the street, return them to their homes or expose them to therapeutic homes, without any support from the network.
Descriptors: Mental Disorders; Family; Caregivers.

RESUMEN | Objetivo: Verificar la literatura científica sobre los desafíos que enfrentan los familiares en el cuidado de personas con Trastornos Mentales. Método: Esta es una revisión integradora. Se realizó la búsqueda de artículos; con delimitación en los últimos 5 años (2015-2020); en portugués, inglés y español; disponible en su totalidad. En las siguientes plataformas de datos: DOAJ, LILACS, MEDLINE, SciELO, SCOPUS y Web of Science. Resultados: Los datos se organizaron y presentaron en figuras y tablas. De los 5740 estudios encontrados, 160 estaban disponibles en DOAJ, 123 en LILACS, 3056 en MEDLINE, 28 en SciELO, 834 en SCOPUS y 1539 en Web of Science. Sin embargo, después de la lectura, solo quedaron los que cumplieron con los criterios de inclusión y exclusión descritos en la metodología, 9 estudios. Conclusión: Se observa que las instituciones no están preparadas para poner a las personas con trastornos mentales en la calle, devolverlas a sus hogares o exponerlas a hogares terapéuticos, sin ningún apoyo de la red.
Descriptores: Transtornos Mentales; Família; Cuidadore.

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INTRODUCTION

The asylum model was in resonance with the Health Policies of Brazil that had its landmark in the 8th National Conference on Health (1986), in the 1st National Conference on Mental Health (1987), in the 2nd National Conference on Mental Health (1992) , culminating in the 3rd National Conference on Mental Health (2001). (1)

The family affected with the relative with a mental disorder implies considering the transformation of the person formerly known to behaviors of isolation, self-destruction, aggressiveness and inadequate hygiene habits, which can generate anxiety, anger, guilt, fear and anguish for the caregiver. In addition to the tasks acquired such as regularly accompanying them to health services, administering medication, providing social support, paying for treatments and overcoming the difficulties of these tasks, encouraging social interaction, experiencing constraints, prejudices and stigmas in relation to the person affected. Thus, the caregiver is predisposed to the development of mental suffering and impairment of social, occupational and financial life, as the demands of the person with mental disorder can become an experience lived as a burden for the caregiver. (2)

The National Mental Health Policy proposes that mental health practices in primary care replace the traditional medicalizing model. Therefore, the articulation of the care network is necessary, aiming at the integrality of this individual in primary care and in the family health strategy, as these are the preferred gateway to the entire Health System, including with regard to mental health needs of these users. (3) However, it is still up to the family the role of the caregiver, who is the individual who is willing to provide the patient with necessary care, often exposing themselves to the risk of compromising their own health for the benefit of the patient. (4)

> “The family affected with the relative with a mental disorder implies considering the transformation of the person formerly known to behaviors of isolation, self-destruction, aggressiveness and inadequate hygiene habits, which can generate anxiety, anger, guilt, fear and anguish for the caregiver”

This research arose from the need for a family member who takes care of a person living with a mental disorder to describe the difficulties faced in caring for the loved one and their anguish in the ineffectiveness, often, of care with health services, education and the social support network . This deviates from the principles of the Unified Health System (SUS) and agreements signed in the historical landmarks mentioned above. The mental health of this family member is fundamental, especially with regard to its structure, as at times it may appear unstructured in the face of daily challenges. Therefore, not only the patient but also the family member who lives must receive support from the support network so that this family can be assisted.

In this context, the main objective of this research was to verify in the scientific literature the challenges faced by family members in the care of people with Mental Disorders.

METHOD

This is a bibliographic descriptive study of the integrative review type, with a qualitative approach that offers opportunities to check the scientific literature and understand the broad research topics, contributing to patient care practices based on scientific knowledge. (5)

From the following steps: (1) elaboration of the guiding question and objective of the study; (2) definition of inclusion and exclusion criteria for scientific productions; (3) search for scientific studies in databases and virtual libraries; (4) analysis and categorization of the productions found; (5) results and discussion of findings. (6)

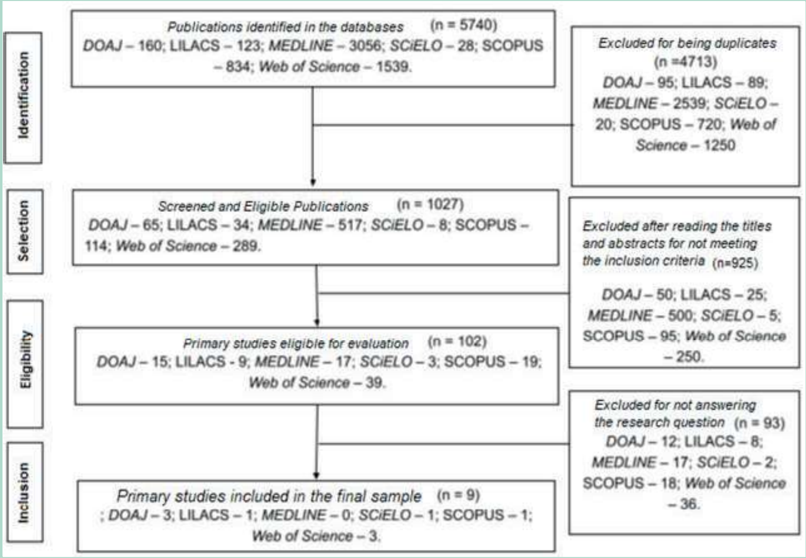
To raise the guiding question, the PICo strategy was used, a methodology that helps in the construction of a research question and search for evidence for a non-clinical research, where P =

Quadro 1 - Estratégia de busca por base de dados. Recife, Pernambuco (PE), Brasil, 2021.

Database	Search Terms	Results	Selected
DOAJ	Mental Disorders AND Family AND Caregivers	160	3
LILACS	Mental Disorders AND Family AND Caregivers	123	1
MEDLINE	Mental Disorders AND Family AND Caregivers	3056	0
SciELO	Mental Disorders AND Family AND Caregivers	28	1
SCOPUS	Mental Disorders AND Family AND Caregivers	834	1
Web of Science	Mental Disorders AND Family AND Caregivers	1539	3
Total		5740	9

Source: Research data, 2021.

Figure 1 - Flowchart of the selection process for primary studies adapted from PRISMA. Recife, Pernambuco (PE), Brazil, 2021.



Source: Research data, 2021.

Population/Patient; I = Interest; and Co = Context (P: Family caregiver; I: Challenges faced by the family; Co: Health of the caregiver who provides assistance to a person with a mental disorder). Thus, the following guiding question of the research was defined: "What are the challenges faced by the family taking care of a person with a mental disorder?".

For selection of articles, the following inclusion criteria were used: original article, available in full, published in the last 5 years (2015-2020) in Portuguese, English or Spanish, that met the objective of the study. Gray literature, as well as repeated publications of studies in more than one database, and articles that did not answer the study's guiding question and that allowed access through the Virtual Private Network (VPN) of the University of Pernambuco (UPE) were excluded. The temporal delimitation in the last 5 years is justified, aiming at the survey of more recent articles.

Data collection took place during the month of June and July 2021 in the following Databases: Directory of Open Access Journals (DOAJ); Latin American and Caribbean Literature on Health Sciences (LILACS); Medical Literature Analysis and Retrieval System Online (MEDLINE); SCOPUS, and Web of Science, as well as the Virtual Scientific Electronic Library Online (SciELO).

Articles indexed from the Health Sciences Descriptors (DeCS) were sought: "Mental Disorders", "Family", "Caregivers". The respective terms from the Medical Subject Headings (MeSH) were used: "Mental Disorders", "Family", "Caregivers". The operationalization and the search strategy were based on the combination with the Boolean operator AND and OR, carrying out the search jointly and individually so that possible differences could be corrected (Chart 1).

The articles were selected based on the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) in order to assist in the development of articles. (7) At first, duplicated studies were eliminated by reading the titles and abstracts. Of these pre-selected ones, a full reading was carried out, in order to verify which ones meet the guiding question and the inclusion/exclusion criteria. The final sample was then constructed with studies relevant to the pre-established criteria (Figure 1).

Once the reading of the articles was consolidated, the selected ones were categorized, classifying the knowledge produced in levels of evidence according to Melnyk & Fineout-Overholt (8): level I, evidence is related to systematic review or meta-analysis of randomized controlled clinical trials or from clinical guidelines based on systematic reviews of randomized controlled clinical trials; at level II, evidence derived from at least one well-designed randomized controlled clinical trial; at level III, evidence from well-designed clinical trials without randomization; at level IV, evidence from well-desig-

Table 1 - Synthesis of the main findings about the challenges faced by the family taking care of a person with a mental disorder. Recife, Pernambuco (PE), 2021.

N	Title/Database	Authors (Year)	Country	Level of Evidence	Objective	Results
1	Stigma and burden of mental illness and their correlates among family caregivers of mentally ill patients. / DOAJ	Ebrahim, Omnya S. et al. (2020)	UK	VI	Explore the experiences of family members who provide home care to patients with severe mental disorders.	The caregivers studied suffer from stigma and a high level of burden.
2	Challenges of Providing Home Care for a Family Member with Serious Chronic Mental Illness: A Qualitative Enquiry. / DOAJ	Mokwena, Kebogile Elizabeth; Ngoveni, Amukelane. (2020)	Switzerland	II	Explore the experiences of family caregivers of people with mental disorders, by examining the loads they face and the coping strategies they use.	Lack of the skills and resources needed to care for the mentally ill at home exposes patients and their families to emotional, financial and social difficulties and results in unfavorable outcomes for both patients and their families.
3	An Exploration of Family Caregiver Experiences of Burden and Coping While Caring for People with Mental Disorders in Saudi Arabia—A Qualitative Study. / DOAJ	Sharif, Loujain et al. (2020)	Saudi Arabia	VI	Explore the experiences of family caregivers of people with mental disorders, by examining the loads they face and the coping strategies they use.	Family caregivers of people with mental disorders face a series of burdens and stressors, such as associative stigma and burnout. These burdens are often due to their role of caring combined with insufficient support or ineffective coping strategies, which can affect their quality of life and biopsychosocial integrity, which, in turn, can affect the care they provide.
4	Burden of family caregivers of people with mental disorders: analysis of health services. / LILACS	Eloia, Sara Cordeiro et al. (2018)	Brazil	VI	To analyze the degree of objective and subjective burden felt by family caregivers of psychiatric patients.	There was a greater burden with regard to supervision of problematic behaviors and the impact on daily routines.
5	Minor psychiatric disorders and their associations in family caregivers of people with mental disorders. / SciELO	Treichel, Carlos Alberto dos Santos et al. (2017)	Brazil	VI	To analyze the occurrence of minor psychiatric disorders and their associations in family members of people with mental disorders.	A higher prevalence of these disorders was strongly associated with female gender, older age, first-degree family ties, not having a paid job, lower education level, lower income, health problems, poor quality of life and feeling of burden.
6	Barriers to Family Caregivers' Coping With Patients With Severe Mental Illness in Iran. / SCOPUS	Ebrahimi, Hossein et al. (2018)	Iran	VI	Identifying the wide spectrum of problems caused by caring for a patient with mental illness imposes a great burden on family caregivers	The results consisted of four main categories: isolation of the patient from everyday life, incomplete recovery, lack of support from the health system, and stigmatization.

7	The experience of caregivers of people living with serious mental disorders: a study from rural Ghana. / Web Of Science	Ae-ngibise, Kenneth Ayuurebobi et al. (2015)	Ghana	VI	Assess the burden of care on caregivers of people living with mental disorders.	Emotional suffering, stigma, financial burden, lack of support networks, social exclusion, impact on health and absence of decentralized mental health services were experienced by family caregivers.
8	Family caregiver burden in mental illnesses: The case of affective disorders and schizophrenia - a qualitative exploratory study. / Web Of Science	Von Kardorff, Ernst et al. (2015)	Germany	VI	Explore the specific burdens experienced by caregivers of patients with schizophrenia and affective disorders.	Taking care of a person with mental illness affects caregivers emotionally, financially, physically and causes some restrictions in their routine (daily annoyances). Finally, it causes conflicts in family relationships.
9	Factors associated with the burden of family caregivers of patients with mental disorders: a cross-sectional study. / Web Of Science	Souza, Ana Lúcia Rezende et al. (2017)	Brazil	VI	Identify factors associated with the burden of caregivers of family members with mental disorders.	Factors independently associated with caregiver burden were depression, being over 60 years of age, not receiving care assistance, recent patient crisis, days of contact, and having other family members in need of care.

Source: Research data, 2021.

ned cohort and case-control studies; at level V, evidence from a systematic review of descriptive and qualitative studies; at level VI, evidence derived from a single descriptive or qualitative study; and at level VII, evidence derived from the opinion of authorities and/or report from expert committees.

The summary of the corpus information was elaborated through an instrument: identification of the original article; article authorship; year of publication; parents; methodological characteristics of the study; and study sample. Allowing itself to obtain general conclusions due to the gathering of several studies, through the process of systematic analysis and synthesis of the researched literature. When well elaborated, it can represent the current state of the researched literature. Furthermore, it highlights the knowledge gaps that need to be filled with further studies.

In order to have a better understanding and visualization of the main findings, the data were organized and presented in figures and tables, exposed in a descriptive way.

RESULTS

The selected studies are arranged so as to highlight their titles, authors, years of publication, levels of evidence, objectives and results. After reading the selected articles, the studies were categorized, classifying the knowledge produced on the topic, in levels of evidence, mostly level VI - evidence derived from a single descriptive or qualitative study. The main findings set out in the objectives and conclusions are directly associated with the challenges faced by the family taking care of the person with a mental disorder (Table 1).

Given the above, it is observed that among the biggest challenges faced by family caregivers is the burden, especially on female caregivers. Those who find themselves alone and often without the support of the health team. This support is essential from the first moment, aiming at the health not only of the patient but also of their caregiver.

DISCUSSION

At the end of the searches in the databases, selection of articles, reading and analysis of them, the categorization of terms was evidenced, which portray and describe what the literature on this topic brings, but mainly the answers and the confrontations experienced by the relatives of people with mental disorders, the difficulties faced by them, and especially for this person living with mental disorder, the fact of how difficult their (re)insertion in the family and society is after long years outside the social and family context. Below are described some categories found.

Family estrangement

The family is constituted based on cultural kinship relationships, being historically determined, including among the basic institutions, identified as a key element not only for the survival of individuals, but also for the protection and socialization of its components, transmission of the cultural and economic capital and group ownership, as well as gender relations and solidarity between generations. Through it, behavior patterns, moral, social, ethical and spiritual values are incorporated. (9)

The family of the person in psychological distress, from the emergence of psychiatry as medical knowledge, responsible for unveiling madness, was removed from the treatment of their relative, as he was in a psychiatric hospital. In this model, the family member was excluded from the treatment, feeling guilty due to the prohibition of visits. (10)

In the institutionalization of madness, in which medical knowledge becomes the holder and dominator of the then "mental patient", the separation of individuals from their social and family environment became a premise of the treatment proposed at that time, as the family was seen as a cause of illness, further reinforcing the need for isolation as a therapeutic measure. The family's relationship with the asylum was one of complicity in the patient's hospitalization, translated into the gratitude of these family members in seeing themselves relieved of the problem. (11)

With the psychiatric reform and the deinstitutionalization of psychiatric hospitals, the caregiver becomes the family or relative who assumes this role, who are responsible for the person with a mental disorder. A family caregiver is understood as a person who, through parental ties, assumes direct or indirect responsibility for the care of a sick and/or dependent family member. (12)

Conflicts in the family context

Family conflicts are imminent when the family experiences a family member's illness situation, as differences in the availability for care, as well as the interest and aptitude for it, can lead to the need for intervention by a health professional through a clinical posture and constant guidelines for patient care, which can ease the experience of care provided by the caregiver, which contributes to the reduction of family conflicts in relation to the patient and their care needs (13)

It is noteworthy that the burden of family caregivers is a stressful factor. The caregiver assumes multiple roles, becoming the "only caregiver", eventually assisted in smaller tasks by other family members, a fact that leads to physical and mental exhaustion, which can harm the disease control and the quality of life not only of the patient, but of the whole family. (14)

In this situation, conflicts of all kinds can be alleviated when the health professional provides care, but also identifies the main caregiver, guiding the needs of direct and indirect care to this person, contributing to the reduction of anxiety and anguish experienced by the family as a whole. A person who takes care of another person during the experienced process becomes de-personified, loses family characteristics and progressively assumes another way of being. (14)

Mental Health and Citizenship

Federal Law No. 10,216, of December 6th, 2001, guarantees the rights of people with mental disorders, including those related to the use of psychoactive substances. In general, Law No. 10.216/2001 assures people who benefit from SUS actions and services the right to treatment that respects their citizenship and that, therefore, should preferably be carried out in community or territorially based services, therefore, without excluding them from coexistence in society. (14, 15)

It is essential, therefore, to actively include in the expansion, formulation and evaluation of Primary Health Care the Mental Health Actions that, with transversal potential, should help the teams to work on the dimension of psychological distress, which is more than a simple threat to biological integrity, as well as to your integrity as a human being, as a subject of action and reaction, who has its own specific needs. (15-17)

Performing the search strategies was found a small sample and little availability of scientific articles to compare the results. As well as few articles were raised as a result of the descriptors, few met the objective of the study. Furthermore, the included studies have limitations such as: single centers, different comparison systems, small sample size and lack of randomization.

Thus, it is not possible to prove the existence of scientific evidence related to the challenges faced by the family taking care of a person with a mental disorder. Making it necessary to carry out more studies containing a larger sample and enabling discussion of aspects associated with the topic.

CONCLUSION

In this review, it was observed the challenges faced by the family taking care of the person with mental disorder; mainly associated with the unpreparedness of professionals and family members with psychiatric reform and deinstitutionalization. However, even though there is still a scarcity of studies that give real importance to this topic, it is clear how big is the lack of knowledge of professionals about what was to come and of family members who did not know the disease and were not prepared to provide the necessary support.

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