CIÊNCIAS DA VIDA E DA SAÚDE LIFE AND HEALTH SCIENCES CIENCIAS DE LA VIDA Y LA SALUD



Millenium, 2(25)



PROGRAMAS PSICOEDUCACIONAIS PARA CUIDADORES FAMILIARES DA PESSOA COM DOENÇA MENTAL: UMA SCOPING REVIEW

PSYCHOEDUCATIONAL PROGRAMMES FOR FAMILY CAREGIVERS OF THE PERSON WITH A MENTAL HEALTH CONDITION: A SCOPING REVIEW

PROGRAMAS PSICOEDUCATIVOS PARA CUIDADORES FAMILIARES DE PERSONAS CON ENFERMEDAD MENTAL: UNA REVISIÓN DE ALCANCE

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RECEIVED: 02nd August, 2024

REVIEWED: 31st August, 2024

ACCEPTED: 26<sup>th</sup> September, 2024 PUBLISHED: 18<sup>th</sup> October, 2024



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## **RESUMO**

**Introdução:** A incapacidade do cuidador familiar de uma pessoa com doença mental para exercer o seu papel, implica que a prestação dos cuidados recaia sobre as instituições de saúde às quais se associam custos acrescidos. Neste sentido, é fundamental capacitar estes cuidadores, através da implementação de programas psicoeducacionais. Estes são uma forma de educação para a saúde mental, onde se pretende dotar as pessoas de conhecimentos através de uma componente educativa e de suporte emocional.

**Objetivo:** Mapear, analisar e sintetizar os programas psicoeducacionais do cuidador familiar de uma pessoa com doença mental e /ou psiquiátrica, desenvolvidos em contexto português.

**Métodos:** Foram seguidos os passos metodológicos de uma scoping review de acordo com JBI. Efetuada a pesquisa em diferentes bases de dados como CINAHL, Academic Search Complete, Educational Resource Information Center (ERIC), Medline complete, Psychology and Behavioral Sciences Collection (todas via EBSCOhost) e como fonte de literatura cinzenta foi usado o Repositórios Científicos Abertos de Portugal (RCAAP).

**Resultados:** Foram identificados oito programas de psicoeducação, estabelecendo-se dois grandes grupos: cuidadores familiares de pessoas com demência e cuidadores familiares de pessoas com esquizofrenia.

**Conclusão:** É necessário validar programas de psicoeducação já desenvolvidos, assim como sistematizar a informação fornecida / extraída dos mesmos, de forma a implementar a melhor evidência científica. Esta revisão serve como documento de consulta dos programas para o cuidador familiar, sugerindo-se, no futuro, a realização de outras pesquisas que englobem programas internacionais.

Palavras-chave: cuidadores familiares; programas de psicoeducação; enfermagem de saúde mental e psiquiátrica

## **ABSTRACT**

**Introduction:** The inability of the family caregiver of a person with a mental health condition to perform their role implies that care provided is done by health institutions, with which added costs are associated. Therefore, it is fundamental to empower these caregivers by implementing psychoeducational programs. These programs are a form of mental health education aimed at equipping individuals with knowledge through an educational component combined with emotional support.

**Objective:** To map, analyze, and summarise the psychoeducational programs of the family caregiver of a person with mental health and/or psychiatric disorder developed in the Portuguese context.

**Methods:** The methodological steps of the scoping review according to the JBI were followed. The search was carried out in several databases, such as CINAHL, Academic Search Complete, Educational Resource Information Center (ERIC), Medline Complete, and Psychology and Behavioral Sciences Collection (all of which through EBSCOhost). As a source of grey literature, the Repositórios Científicos Abertos de Portugal (RCAAP) was used.

**Results:** Eight psychoeducational programs, with two large groups established: family caregivers of people with dementia and family caregivers of people with schizophrenia.

**Conclusions:** It is necessary to validate already established psychoeducational programs, as well as systematizing the information provided/extracted from them, to implement the best scientific evidence. This review serves as a reference document for family caregiver programs, suggesting further research in the future to also include international programs.

Keywords: family caregivers; psychoeducational programs; psychiatric and mental health nursing

# **RESUMEN**

Introducción: La ausencia o incapacidad del cuidador familiar de una persona con patología mental para desempeñar su papel implica que la provisión de cuidados recaiga en las instituciones de salud, lo que conlleva costos adicionales para todos. En este sentido, es fundamental intervenir con estos cuidadores mediante la implementación de programas psicoeducativos. Estos son una forma de educación en salud mental, cuyo objetivo es dotar a las personas de conocimientos a través de un componente educativo y de apoyo emocional.

**Objetivo:** Realizar un mapeo y síntesis de los programas psicoeducativos o de capacitación para el cuidador familiar de una persona con patología mental y/o psiquiátrica.

**Métodos:** Se siguieron los pasos metodológicos de la revisión de alcance según las directrices del Instituto Joanna Briggs (JBI). La búsqueda se realizó en diversas bases de datos, incluyendo CINAHL, Academic Search Complete, Educational Resource Information Center (ERIC), Medline Complete, Psychology and Behavioral Sciences Collection (todas a través de EBSCOhost). Como fuente de literatura gris se utilizó el Repositorio Científico de Acceso Abierto de Portugal (RCAAP).

**Resultados:** Se identificaron ocho programas psicoeducativos, estableciéndose dos grandes grupos: cuidadores familiares de personas con demencia y cuidadores familiares de personas con esquizofrenia.

**Conclusión:** Es necesario validar programas de psicoeducación ya desarrollados, así como sistematizar la información proporcionada / extraída de los mismos, con el fin de implementar la mejor evidencia científica. Esta revisión sirve como un documento de consulta sobre los programas para el cuidador familiar, sugiriéndose en el futuro la realización de otras investigaciones que incluyan programas internacionales.

Palabras Clave: cuidadores familiares; programas de psicoeducación; enfermería de salud mental y psiquiátrica

#### **INTRODUCTION**

Mental health (MH) is fundamental to the well-being of any human in as much as it is the foundation for a happy, fulfilled, and productive life. However, according to the Health at a Glance report (2018) from the Organization for Economic Cooperation and Development (OECD), 18.4% of the Portuguese population suffers from a mental health condition (OECD/EU, 2018). To this data we can add an ever-ageing population and, as a consequence, the increased incidence and prevalence of conditions that are characteristic of these age groups (OECD, 2019).

The person who suffers from any MH disorder presents some limitations and inability to perform their daily tasks, becoming more dependent on help. Generally, it is the family who assumes the provision of direct and indirect care to their family members (Liu et al., 2020; Schulz et al., 2020).

The transition into the role of caregiver implies a change in the family structure and dynamics. It is a complex process that, over time, can imply the caregiver's wear due to physical and psychological tiredness, leading them to become overburdened (Liu et al., 2020; Sequeira, 2018).

According to the Instituto Nacional de Estatística, in 2019, there were over 1 million family caregivers in Portugal, which represents a positive contribution not only to the caregiver but also to the country's economy (Instituto Nacional de Estatística, 2020). The inexistence or inability of the caregiver to perform their role implies that care provided is done by health institutions, to which inevitably there are added costs to all (Sequeira, 2018). Therefore, the growing need for assistance to these caregivers is reaffirmed.

In the areas of Psychiatric and Mental Health Nursing (PMHN), a large part of the assistance to the Family Caregiver (FC) is the implementation of psychoeducational interventions, since they enhance the personal adequation of the caregiver to the situation, developing the caregiver's ability to care and making it easier for them to adapt to their role (Bressan et al., 2020; Cheng et al., 2020; Sin et al., 2017).

For Amaral et al. (2020) the psychoeducational intervention is a specific form of MH education that focuses on health attitudes and behaviors. As such, this intervention aims to provide knowledge to individuals through an educational component as well as an emotional support component through the management of emotions and expectations, among others. According to these authors, this intervention should be framed and limited in time, structured into sessions, using the problem-solving technique. The focus of the intervention should be fundamentally on empowering the caregiver by imparting theoretical or practical knowledge, aiming to improve the person's, family, or community's MH literacy (Amaral et al., 2020).

However, the information about the different psychoeducational intervention programs aimed at the FC is dispersed, which makes evidence-based practice difficult. Thus, this study aims to map, summarise, and synthesize the psychoeducational or empowering programs for an FC of a person with a mental or psychiatric condition, in which there is an active participation of the generalist nurse and/or the Psychiatric-Mental Health Nurse Specialist (PMHNS) in elaborating and/or implementing it.

## 1. METHODS

Methodologically, it was chosen to carry out a Scoping Review, according to the JBI guidelines (Peters et al., 2015) and the flow diagram - Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021).

## 1.1 Research guestion

The research question in this study is: "What are the psychoeducational or empowering programs for the FC of the person with a mental health and/or psychiatric condition in Portugal?". To complement the study and the analysis of the evidence found, the following subquestions were asked: a) "What are the main objectives, features, and contents of the programs?"; b) "What is the level of validation of the studies that originated the program?".

# 1.2 Inclusion and exclusion criteria

# 1.2.1 Population

In the present study, all of the studies that involved male or female FCs who cared for an adult over 18 years old with any level of education and with a mental health and/or psychiatric condition were considered.

## 1.2.2 Concept

The studies that were included approached psychoeducational or empowering programs that were elaborated or implemented by the generalist nurse and/or PMHNS and that empowered the FC in domains of mental or psychiatric health. All the programs encountered were included in the study, regardless of the evidence level for their elaboration and implementation or of the efficacy level evaluated after the implementation. Thus, considering the methodology of complex interventions of Craig et al. (2012) and Skivington et al. (2021), the programs were categorized into three levels of validation: weak, moderate, and robust.

From this perspective, a program was considered weak when the evidence-based theoretical rationale lacked at least one sustained literature review, so the subsequent steps, even if done rigorously, may be compromised. Concerning the moderate level of validation, the program was classified as such when it presented a sustained literature review based on an experimental study design with pre-test and post-test. For a robust validation level, all the previous steps were done with methodological rigor and validation techniques of the focus group or Delphi study kind (Craig et al., 2012; Skivington et al., 2021).

## 1.2.3 Context

For this study, all the programs done and/or implemented in any context of care in the national geographical unit were included.

# 1.2.4 Types of study

Quantitative, qualitative, or mixed studies, systematic literature reviews, and all grey literature were included in the study without a time limit for publication as long as they were presented in Portuguese, English, or Spanish.

# 1.3 Research strategy and study selection process

After a brief analysis of the state of the art regarding the theme and definition of the most used terms, a concept map was done. Afterward, database research was done in CINAHL Academic Search Complete, Educational Resource Information Center (ERIC), Medline Complete, and Psychology and Behavioral Sciences Collection (all via EBSCOhost). As grey literature, Repositórios Científicos Abertos de Portugal (RCAAP) was used. The research equation was adapted to each of the databases and repositories. Just as predicted, the data selection process was done and described rigorously by three authors, who worked in pairs (AB, IE, RS) and independently agreed on the articles to include.

After doing the research as per the methodology applied, a total of 36 documents were obtained in RCAPP, 59 articles through EBSCO, and an article and a document obtained through secondary sources, completing a total of 97 registers identified for analysis.

Next, the duplicate registers were removed. The title and summary were read, excluding the registers that did not meet the inclusion criteria. The inclusion criteria were once again applied to the registers resulting from the previous step, resulting in eight programs for data analysis.

All these operations are represented in PRISMA, Figure 1, adapted from Page et al. (2021).

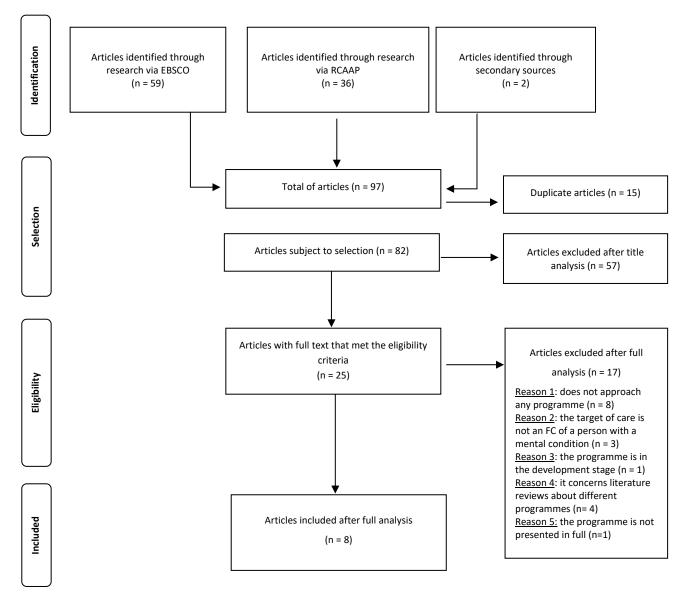


Figure 1 - Flow diagram of study sorting, selection, and inclusion (Page et al., 2021)

#### 2. RESULTS

## 2.1 Features and contents of the studies included

# 2.1.1 Which psychoeducational or empowering programs for the FC of the person with a mental health and/or psychiatric condition in Portugal?

From the analysis included in this study, four of them refer to dementias, in one of them is aimed exclusively at FCs of people with Alzheimer's disease (Afonso, 2022; Guerra, 2012; Sousa, 2017; Teles et al., 2022), three of the programs are aimed at FCs of people with schizophrenia (Marques, 2014; Nunes, 2022; Sousa, 2013) and, lastly, a program is aimed at FCs of people with psychotic symptoms (Rodrigues, 2021).

As for the type of intervention, four main typologies exist in the encountered programs; individual intervention (Afonso, 2022), intervention of a multifamily group in the absence of the patient (Guerra, 2012; Rodrigues, 2021; Sousa, 2013), multifamily intervention in the presence of the patient (Marques, 2014) and, lastly, interventions with individual sessions and multifamily sessions in the absence of the patient (Nunes, 2022; Sousa, 2017).

The number of sessions between programs showed some disparities, ranging from three (Marques, 2014) to nine sessions (Rodrigues, 2021; Sousa, 2017), with an average of five to six sessions per program.

More than 50% are implemented in a community context (Afonso, 2022; Guerra, 2012; Marques, 2014; Nunes, 2022; Sousa, 2013), only one of the programs takes place in a hospital environment (Rodrigues, 2021) and one of them can occur in a hospital or community environment (Sousa, 2017).

Most programs are promoted by a PMHNS (Afonso, 2022; Nunes, 2022; Rodrigues, 2021; Sousa, 2017; Sousa, 2013), and only two are promoted by a multidisciplinary group (Guerra, 2012; Marques, 2014). It is important to mention that a large part of the programs were built by a PMHNS as a result of academic work (Afonso, 2022; Marques, 2014; S. Nunes, 2022; Rodrigues, 2021; Sousa, 2017; Sousa, 2013), with only two of them designed by other professional groups but with the necessary collaboration of a nurse (Guerra, 2012; Teles et al., 2022). It should be noted that all the programs, except for "iSupport," are performed in an inperson format, whereas this one is done in an online format.

Table 1 - Programme features and contents

Programme, Author and	Family caregiver of a person with	Intervention type Psychoeducational programme			Sessions			Cont ext	Promoters	Format
Year										
		Individual	Multifamily group in the presence of the patient	Multifamily group in the absence of the patient	Duration of the programm e	Nr. of sessions	Session duration			
(Es)Tar com a Demência (Sousa, 2017)	Dementia	<b>✓</b>	·	√ ·	7 weeks	7 individual sessions and 2 group sessions	60 individual minutes, 90 group minutes	Com munit y and hospi tal	PMHNS	In person
HELP to HELP (Rodrigues, 2021)	Psychotic symptomatol ogy			<b>√</b>	10 to 11 weeks	8 to 9 sessions	60 to 90 minutes	Hospi tal	PMHNS	In person
Uma intervenção psicoeducativa na gestão da sobrecarga do cuidador informal de pessoa com esquizofrenia (Marques, 2014)	Schizophreni a		<b>√</b>		3 months	3 sessions	About 90 minutes	Com munit y	Multidisciplinar y group	In person
Curae de mim (Afonso, 2022)	Alzheimer	✓			6 weeks	6 sessions	60 minutes	Com munit V	PMHNS	In person
Redução da Sobrecarga do Cuidador de Pessoa com Esquizofrenia: Intervenções de Enfermagem (Nunes, 2022)	Schizophreni a	<b>√</b>		✓	8 weeks	2 individual sessions and 6 group sessions	30 individual minutes and 60 group minutes	Com munit y	PMHNS	In person
Família unida (Sousa, 2013)	Schizophreni a			✓	7 weeks	7 sessions	110 minutes	Com munit y	PMHNS	In person
ProFamílias-demência (Guerra, 2012)	Dementia			✓	8 months	6 sessions	About 90 minutes	Com munit y	Multidisciplinar y group	In person
iSupport– Portugal para quem apoia na demência (Teles et al., 2022)	Dementia	<b>√</b>				23 sessions		-	In case it is necessary, they can have the collaboration of health care or social care professionals.	On-line

# 2.1.2 What is the level of validation of the studies that originated the programs?

The relationship between the criteria used to categorize the programs and the corresponding data is summarized in Table 2. Only one of the programs did not go beyond the design stage, i.e., due to the pandemic, it was neither implemented nor assessed in clinical practice (Rodrigues, 2021). The remaining programs present an experimental trial as study design, all of them with preand post-tests, regardless of the methodology applied to this assessment (Afonso, 2022; Guerra, 2012; Marques, 2014; Nunes, 2022; Sousa, 2017; Sousa, 2013; Teles et al., 2022).

Considering the a priori classification, it is verified that three of the programs present, as a basis for their design, studies with methodological weaknesses (Afonso, 2022; Marques, 2014; Sousa, 2013). Therefore, only one programme is categorised as robust (Teles et al., 2022) and two as tendentially robust (Guerra, 2012; Sousa, 2017). One program presents a moderate level of validation (Nunes, 2022), two are between weak and tendentially moderate (Marques, 2014; Rodrigues, 2021), and two of the programs are categorized with a weak level of validation (Afonso, 2022; Sousa, 2013).

**Table 2** – Categorisation of the programmes based on the level of validation

Study title (Author and Year)	Program study design	Types of study as the basis for building the program and respective interventions	Level of validation of the programme	Program implementation
Criação e Validação de um Programa de Capacitação para Cuidadores Familiares de Pessoas com Demência (Sousa, 2017)	Controlled randomized experimental study	Two integrative literature reviews and a Focus Group	Tendentially robust	Yes
HELP to HELP — Um Programa de Literacia em Saúde Mental Multifamiliar Rodrigues, 2021	Integrative literature review	Integrative literature review according to the IBI methodology to determine the MH literacy interventions that demonstrated efficiency and benefits to the informal caregivers of people with psychotic symptomatology.	Weak to tendentially moderate	No
Uma intervenção psicoeducativa na gestão da sobrecarga do cuidador informal de pessoa com esquizofrenia (Marques, 2014)	Experimental design study, with pre-test, post-test, and randomized control group	Literature review with methodological weaknesses.	Weak to tendentially moderate	Yes
Curae de mim – A Prática Especializada de Enfermagem de Saúde Mental e Psiquiátrica na Intervenção com Cuidadores Familiares (Afonso, 2022)	Experimental design study, with pre-test, post-test	Literature review with methodological weaknesses.	Weak	Yes
Redução da Sobrecarga do Cuidador de Pessoa com Esquizofrenia: Intervenções de Enfermagem (Nunes, 2022)	Experimental design study, with pre-test, post-test	Systematic literature review as per the IBI methodology, to map the effective nursing interventions in reducing overburden in the caregiver of a person with schizophrenia.	Moderate	Yes
Intervenção psicoeducativa em grupo: Prestadores de Cuidados Informais da Pessoa com Esquizofrenia (Sousa, 2013)	Experimental design study, with pre-test and post-test through Gibbs' reflexive cycle (1988)	Literature review with methodological weaknesses.	Weak	Yes
Demência e intervenção familiar: visão sistémica e desenvolvimental (Guerra, 2012)	Experimental design study, with pre-test, post-test	The assessment methodologies involved mostly qualitative methods such as focus group interviews, individual interviews and the photovoice technique.	Tendentially robust	Yes
Feasibility of an online training and support program for dementia carers: results from a mixed-methods pilot randomized controlled trial (Teles et al., 2022)	Randomised controlled pilot trial of mixed methods	The adaptation of iSupport was put into operation in five stages: needs assessment; content translation by an authorised translator and verification of the technical veracity by health professionals; cultural adaptation; independent content assessment by a specialist panel; and accuracy verification by the programme authors.	Robust	Yes

# 2.1.3 What are the main objectives and program contents?

The programs aimed at the FC of people with dementia, where the program aimed at the FC of the person with Alzheimer's is also included, often have more than one objective. These are empowering the FC, training competencies, facilitating the family's

adaptation to the condition of the patient, lowering FC overburden, and MH promotion. In this scope, the themes approached are related to the information about the disease and the pharmacological and non-pharmacological treatment, competence coaching in care and strategies to deal with changed behavior and care toward the person, namely in what concerns safety and the physical environment. Awareness-related themes regarding the caregiver's identity, maintaining their physical and mental health, emotions, feelings and uncertainties surrounding their role, coping and problem-solving strategies, among others listed in the figure (Afonso, 2022; Guerra, 2012; Sousa, 2017; Teles et al., 2022) are also approached.

As for the programs guided toward the FC of people with schizophrenia, in which the study aimed at the FC of a person with psychotic symptomatology can be included, the most common objectives are: lowering FC overburden, empowering through increasing MH literacy, lowering stigma, and promoting active participation in the care process. Regarding the themes approached, these concern knowledge about the condition, pharmacological and non-pharmacological treatment, problem-solving and coping strategies, positive communication, and adaptive family dynamics. They also mention approaching the FC's stress management, community resources psychosocial rehabilitation, and legislation regarding MH (Marques, 2014; Nunes, 2022; Rodrigues, 2021; Sousa, 2013).

# 3. DISCUSSION

The results from the present study show that there are eight psychoeducational or empowering programs for the FC of the person with a mental health and/or psychiatric condition in Portugal. From the data analysis, two areas can be perceived as predominant in these programs: aimed at the FC of the person with schizophrenia and aimed at the caregiver of the person with dementia. In both cases, the rationale for the intervention to the FC is due to the constant need to readapt to the needs of the patient due to the extended evolution of the disease and to the thought and behavior changes shown by the patient (Marques, 2014; Nunes, 2022; Rodrigues, 2021; Sousa, 2017). Thus, it is common that the objectives of the psychoeducation or empowering programs are related to empowering the FC and lowering their overburden.

This is sustained by the literature that validates that psychoeducation has positive effects in lowering overburden and even in the quality of life of the FC (Okafor & Monahan, 2023). However, Bressan et al. (2020) also warn of the need to create sensitive and customized interventions through educational programs adapted to the real needs of the FC.

Therefore, the programs with a robust or tendentially robust validation level can meet the criteria of including more sensitive interventions with higher scientific evidence (Craig et al., 2012; Skivington et al., 2021). In fact, some of the programs present methodological weaknesses in what concerns study design or sample size of the studies in which the design is based or in the rationale for interventions. However, in spite of this, many of them show some rigor in the remaining stages. As such, this review does not evaluate the efficacy of the programs; it only aims to categorize their level of validation. For this reason, it was chosen to include all the programs, regardless of their level of validation, due to considering that this knowledge can be useful to future studies since these studies can provide continuity to the validation and robustness process of these programs.

For this same reason, all the programs designed and/or elaborated by a generalist nurse and/or PMHNS were included, with the suggestion that in the future, they shall be applied by the PMHNS. According to Okafor and Monahan (2023), PMHNSs are well positioned to execute these psychoeducation or empowering programs for the FC since they have very close contact with them, understanding their needs well (Okafor & Monahan, 2023).

In the programs presented, the average number of sessions is five or six; some programs, however, do not count as a session, neither the initial nor the final FC assessment moments. From the literature review done by Okafor e Monahan (2023), they concluded that the programs can have between four to 18 sessions, which allowed them to conclude that both shorter and longer programs are effective in lowering the FC's overburden.

Most programs are implemented in the community context, and only one is in a hospital context, more specifically in the outpatient unit. However, several studies emphasize the importance of continuity of care between hospital and home settings to reduce the stress experienced by family caregivers during the post-discharge period. To achieve this, they recommend using caregiver assessment tools (ranging from burden, knowledge, and ability to care) during the family member's hospitalization. This information can serve as a foundation for providing holistic and personalized support to caregivers at discharge, particularly in the home environment. As a result, effective and sustainable programs are being developed that bridge the transition from hospital to home, functioning as a support system for family caregivers. These programs equip caregivers with the necessary skills and knowledge to fulfill their role while also offering essential emotional support to sustain long-term care (Chan et al., 2022). In this regard, integrating psychoeducation during acute hospital stays could prepare family caregivers to better handle the challenges once the patient is discharged.

Among the presented programs, the "iSupport" program, stands out from the rest since it is presented in an online format, in which the caregiver can do the 23 sessions at their own rhythm and in a context of their choosing, alone or, if needed, in collaboration with health or social care professionals (Teles et al., 2022). Increasingly, the efficacy and advantages of using these kinds of apps or online platforms are being studied because of their relatively low cost and because they allow users to use them at any time and at any moment (Leng et al., 2020). As such, this program, "iSupport," works as a resource that the PMHNS should know, not as much by their implication during the program but for considering it a relevant tool for the psychiatric nurse's practice so that they can recommend it and encourage the FC to participate in it.

## **CONCLUSION**

This work strived to map, analyze, and summarise the programs designed for the FC of a person with mental health and/or psychiatric disorder, with the aim of elaborating a reference document, but essentially as a work for future studies, allowing the development and growth of knowledge in Nursing.

Despite the methodological rigor used, this mapping has some limitations. Due to meeting the study timeline, only the programs developed and implemented in the Portuguese context were included; as such, it may be important that in the future, further research is carried out in the same area but that includes international programs as well. The other limitation to highlight is the fact that the number of databases referenced was limited; however, considering the theme and research questions, the databases that would provide the best results were used.

#### **AUTHOR CONTRIBUTIONS**

Conceptualization, R.S. and C.S.; data curation, I.E.C., A.B. and R.S.; formal analysis, I.E.C. and A.B.; methodology I.E.C. and R.S.; validation, I.E.C., A.B., R.S. and C.S.; writing-original draft, I.E.C. and R.S.; writing-review and editing, I.E.C. and R.S.

## **CONFLICTS OF INTEREST**

The authors declare no conflict of interest.

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