

# Challenges and barriers in mental healthcare systems and their impact on the family: A systematic integrative review

Ángela Carbonell MSW, PhD Candidate<sup>1</sup>  | José-Javier Navarro-Pérez PhD, Associate Professor<sup>1</sup>  | Maria-Vicenta Mestre PhD, Professor<sup>2</sup> 

<sup>1</sup>Inter-University Research of Local Development (IidL) and Social Work and Social Services Department, University of Valencia, Valencia, Spain

<sup>2</sup>Basic Psychology Department, University of Valencia, Valencia, Spain

## Correspondence

José-Javier Navarro-Pérez, Social Work and Social Services Department, Faculty of Social Sciences, University of Valencia, Tarongers Avenue, 46022 Valencia, Spain. Email: J.Javier.Navarro@uv.es

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## Abstract

The aim of this systematic integrative review is to analyse the challenges and barriers found in mental healthcare systems and the impact they have on the family. Searches were made of the Web of Science, Scopus, Medline and Cochrane databases using terms relating to mental health, family care and healthcare systems. We included and critically evaluated studies published in English between 2015 and 2019 that directly or indirectly analysed public mental health policies and the consequences they have for the family. We analysed our findings following the inductive content analysis approach. A total of 32 articles that met quality indicators were identified. Very closely related structural, cultural, economic and healthcare barriers were found that contribute to the treatment gap in mental health. The family covers the care systems' deficiencies and weaknesses, and this leads to overload and a diminishing quality of life for caregivers. It is acknowledged that people with mental illness and their families should be able to participate in the development of policies and thus contribute to strengthening mental healthcare systems worldwide.

## KEYWORDS

family care, health systems, mental health, treatment gap

## 1 INTRODUCTION

The World Health Organization (WHO) (2007) defines a health system as the sum total of all the organisations, institutions and resources that aim to improve the health of the population they serve. It should provide adequate and financially fair services, quality universal healthcare and resources, and protect everybody's right to health through professional or non-professional support (Semrau et al., 2015). The WHO (2010) designates six core components of a health system—leadership and governance; service delivery; health workforce; health information system; medical products, vaccines and technologies; and health system financing—that can be used to determine the quality, coverage and validity of its operations (Manyazewal, 2017). The development of these systems has generally been analysed according to the World Bank's (2019) classification of countries by income (Lora, Hanna, & Chisholm, 2017) into

four separate groups, which in turn are usually categorised into two wider groups in the literature: low- and middle-income countries (LMICs) and high- and middle-income countries (HMICs).

Mental disorders today account for 13% of the burden of disease globally, with this figure being expected to rise to 15% by 2030 (Murray et al., 2012). It is estimated that 450 million people worldwide have a mental disorder and that 25% of the population will suffer from mental illness at some time in their lives (WHO, 2017). Despite the increasing prevalence of mental illness, mental healthcare systems are typically deficient or non-existent all over the world. Various studies have analysed the existence of barriers and limitations in the use of and access to mental health services. Kpobi, Swartz, and Ofori-Atta (2018) report that 28% of countries have no specific budget for mental health and that, of those countries that provide real spending figures, 36% allocate less than 1% of their total health budget to mental health. Rathod et al. (2017) point

out that around 25% of countries today have no legislation on mental health and 40% have developed no healthcare policies in this area. The studies by Abdulmalik et al. (2019) and Ebrahimi et al. (2018) conclude that this deficient funding and limited access to mental healthcare results in a treatment gap and in patients and family members themselves having to shoulder the high costs in economic and psychosocial terms. Sashidharan, White, Mezzina, Jansen, and Gishoma (2016) and Drake, Binagwaho Martell and Mulley (2014) point out that, despite having market-driven or state-planned mental healthcare, HMICs have created expensive and inefficient mental healthcare services that are not universal and do not allow for the sufficient involvement of people with mental illness and their families.

Not only the WHO but also various authors and research papers have developed instruments, innovations and programmes for improving access to healthcare and the quality of mental healthcare services (Bouras et al., 2018; Saraceno & Dua, 2009). Notable among these are the WHO's Assessment Instrument for Mental Health Systems (WHO-AIMS) (WHO, 2005) and its mental health Gap Action Programme (mhGAP) (WHO, 2008, 2016), both of which aim to gather essential information on different healthcare systems and strengthen the commitment of governments and international organisations to increase the allocation of financial and human resources to mental illness, especially in those countries that carry a large proportion of the world burden of mental disorders. Despite the gradual success of these programmes (WHO, 2009), investigations by Caulfield, Vatansver, Lambert, and Van Bortel (2019) and Salisbury, Killaspy, and King (2016) identify latent challenges such as a lack of consensus on definition, the implementation of deinstitutionalisation, government apathy, stigma and other treatment barriers as being system challenges that exacerbate the current state of mental health all over the world. A study by Kilbourne et al. (2018) points to the decentralisation of care, help-seeking behaviours, the lack of human and institutional resources and government policies as being barriers that hinder access to quality care and continuity in mental health.

Bearing in mind the systems' challenges and barriers, the responsibility for looking after people with mental illness often falls to family members (Von Kardorff, Soltaninejad, Kamali & Shahrabaki, 2016). Providing care for people with mental illness calls for a significant investment of personal resources, and this has a serious impact on quality of life for family caregivers (Dadson, Annor, & Salifu, 2018). In the recent scientific literature, the care burden has been associated with bad health effects including stress, physical exhaustion, anxiety, depression and frustration (Mulud & McCarthy, 2017). Carbonell and Navarro-Pérez (2019) argue that the underfunding and austerity measures affecting healthcare management models place limits on the professional interventions carried out in the area of mental health and the resources allocated to it, thereby forcing the family to become more involved in caring for the person with mental illness.

The literature stresses the need for mental healthcare systems everywhere to be strengthened through improvements in health results, response capability and efficiency, protecting users and their

### **What is known about this subject**

- Mental healthcare systems all over the world are characterised by deficiencies and weaknesses, especially in low- and middle-income countries.
- The scientific literature on mental health research prioritises the analysis of the characteristics and effectiveness of public mental healthcare policies and their impact on the well-being and quality of life of people with mental illness and their family caregivers.

### **What this paper adds**

- Mental healthcare models that are inefficient and inaccessible can also be found in medium- and high-income countries.
- The stigma associated with mental illness acts as a major limiting factor to the creation and development of policies guaranteeing the welfare of people with mental illness.
- The real costs of mental illness are incalculable. The indirect costs are higher than the direct costs.
- The family acts as a stopgap resource to overcome the system's challenges and barriers, taking on the continuous care and the social and employment costs generated in order to guarantee its biopsychosocial well-being.
- In the future, mental healthcare systems all over the world will need to be made stronger.

families from the financial burden associated with illness and healthcare (Kristensen, Sølvhøj, Kusier, & Folker, 2019; Petersen et al., 2017). Along similar lines, according to the results of the investigations underlying the ROAMER project (Forsman et al., 2015; Wykes et al., 2015), a priority in mental health research for European experts is the analysis of the characteristics and effectiveness of mental healthcare policies and their impact on the well-being and quality of life of people with mental illness and their family caregivers. For this reason, the present study aims to summarise the literature and analyse the challenges and barriers in mental health systems and their impact on the family.

## **2 | MATERIAL AND METHODS**

A systematic integrative review was carried out, since this enables heterogeneous research methods to be analysed and thus provide a more comprehensive understanding of the subject. It also has direct applicability to practice and policy (Whittemore, 2005; Whittemore & Knafelz, 2005). The review was carried out in accordance with the basic principles of systematic review—breadth, rigour and transparency (Mallett, Hagen-Zanker, Slater, & Duvendack, 2012)—thus ensuring the synthesis of the evidence and the methodological rigour of the investigation.

## 2.1 | Criteria for study selection

Studies were included that directly or indirectly analyse public mental healthcare policies and their impact on the family. To guarantee the thoroughness of the data, studies were considered eligible for inclusion as long as they met each of the following criteria: a) original articles published in journals with a peer-review process, regardless of study design (including narrative and systematic reviews), b) published over the last five years (2015–2019), and c) published in journals indexed in the Journal Citation Reports (JCR) or Scopus, using Scimago Journal and Country Rank quartiles and impact factors as a reference. The exclusion criteria were: a) studies on the elderly people or other specific collectives without mental illness (people with impairment, Alzheimer's or other neurological or physical illnesses or intellectual disabilities), and b) grey literature (conference proceedings, articles in the press, doctoral theses, etc.) because this is not peer-reviewed.

## 2.2 | Search strategies and information sources

Systematic searches were made of all articles in English published on the Web of Science, Scopus, Medline and Cochrane databases up to 10 May 2019. The search strategy was based on recent articles on mental healthcare policies and their effect on the family. Three groups of keywords were identified. The first of these focused on the descriptive elements of mental health systems (such as "mental health policies", "austerity measures", "underfunded" and "welfare model"). The second group covered the main concepts involved in family care (such as "caregiver", "family burden" and "familism"). Finally, the third group of keywords focused on descriptors such as "mental health" and "mental disorders". These were inserted into the search fields for title, abstract and keywords using Boolean operators as shown in Table 1. Afterwards, the bibliography sections of the eligible studies we recovered were used to identify other relevant studies.

## 2.3 | Data extraction and synthesis

A number of strategies were used to improve analytical rigour. For the identification of articles, the process included the following

**TABLE 1** Terms used in the Boolean search

Mental health system		Family care		Mental health
*mental health system* OR *welfare model* OR *mental health policies* OR *global mental health* OR *austerity measures* OR *underfunded*	AND	*family care* OR *familism* OR *caregivers* OR *family caregiver* OR *family burden*	AND	*mental health* OR *mental disorders* OR *severe mental* illness* OR *mental health care*

steps: selection of records identified in the databases mentioned above, examination of potentially relevant articles, and the application of eligibility criteria to select the papers included in the study. For each article selected, data were extracted relating to the year and place of publication, study design, study sample, journal, impact factor, aims and main findings.

A narrative synthesis of the sources was then carried out using inductive content analysis (Fingeld-Connett, 2014), which consisted of studying the findings of the studies included and analysing the main categories and subcategories emerging from the data collected, amalgamating new information. To obtain the results an open categorisation process was carried out. Following Coffey and Atkinson (2003), the purpose of this was to break down and code the data and group them into different categories and subcategories that shared the same unit of meaning. The coding was constructed using segments of text containing relevant information. Six main categories and 25 subcategories were finally identified as relating to challenges and barriers in the mental healthcare system worldwide: structural barriers, health culture, illness costs, rehabilitation management, biomedical model and alternative care provisions.

Following Bekhet and Zauszniewski (2012), the search of the literature, the selection of studies, the data extraction and coding were carried out by two of the authors (AC and JJNP) working separately. In case of disagreement during the selection process, consensus was reached via discussion with a third author (MVM).

## 2.4 | Quality evaluation of the studies

High-quality journals contribute significantly to academic development in a particular field (Judge, Cable, Colbert, & Rynes, 2007). So as to guarantee the quality of the studies included here, all were published in journals indexed in JCR or Scopus, which are acknowledged as being the most reliable quality indicators and the most highly regarded by organisations that evaluate research activities.

The assessment of risk bias in the studies included was important for determining the validity of the results and the way findings were interpreted. In order to adjust the methodology to the guidelines for carrying out and publishing systematic reviews, we used the PRISMA-P statement (Moher et al., 2015) with a checklist of 17 items, which facilitates the preparation and reporting of a robust protocol for the review.

In addition, the Critical Appraisal Skills Programme (CASP) was used to assess the methodological quality (MQ) of the qualitative and review studies. Each article we included was given a general score. The studies were then grouped according to low quality (0–3 points), moderate quality (4–7 points) and high quality (8–10 points), calculated by dividing the total number of affirmative responses by the total number of "yes", "no" and "can't tell" responses together. No papers were excluded at this point. The Cochrane Collaboration Risk of Bias Tool (CCRB) (Higgins et al., 2011) was also used to assess the MQ of studies that included quantitative results. The CCRB is a

tool with six domains to evaluate the risk of bias: selection bias, performance bias, detection bias, attrition bias, reporting bias and other bias. Due to a lack of consensus on the critical evaluation of studies that use mixed methods (Heyvaert, Hannes, Maes, & Onghena, 2013), any mixed-method studies were evaluated using both the CCRBT and the CASP Qualitative Checklist.

The MQ of and risk of bias in each individual study were assessed by all the authors (AC, JJNP y MVM) independently of each other and all discrepancies were resolved through discussion until a consensus was reached. The full checklists can be found as tables in Appendix S1.

### 3 | RESULTS

A total of 1,539 potentially eligible documents were identified for the systematic integrative review of the literature. After eliminating duplicates, 542 of the 689 remaining documents were rejected for not meeting the inclusion criteria. This left 147 articles, which were assessed for relevance on the basis of title and abstract. This gave us a total of 57 articles, which were then analysed via a full reading of the text. After this stringent selection, 32 articles were finally included in the qualitative synthesis, as shown in Figure 1.

#### 3.1 | Description of the included studies

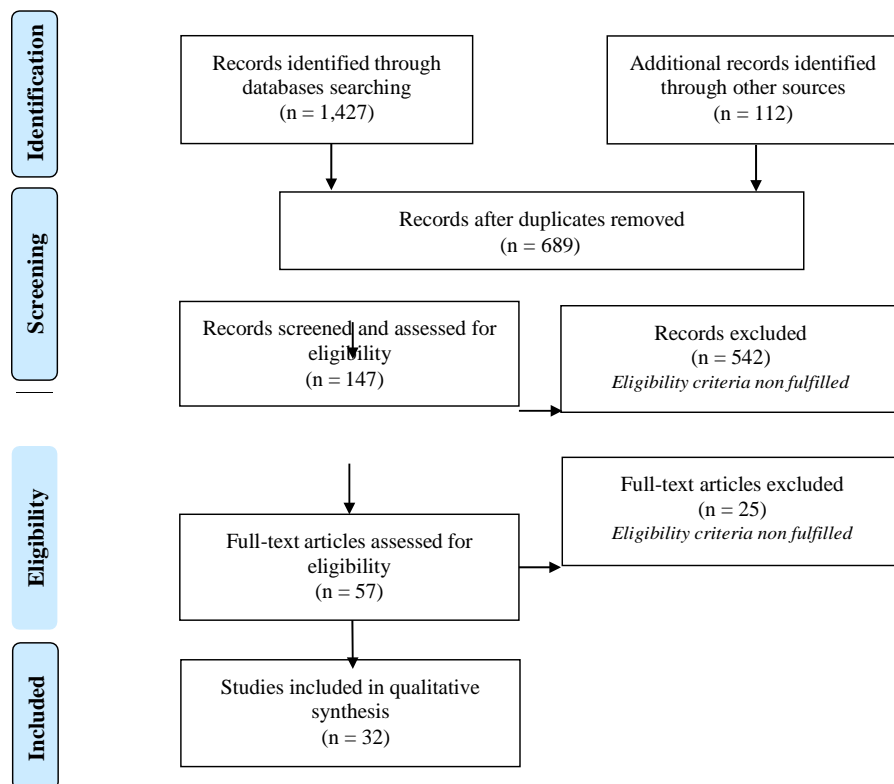
Table 2 lists the methodological characteristics and quality of the 32 studies included. All the articles obtained high or moderate

quality indicators and no risk of bias was found in the quantitative investigations. According to the research methodology there were 11 qualitative studies, 10 review studies, eight cross-sectional quantitative studies and three that used mixed methods. The highest proportion of them (34.4%) used semi-structured interviews to collect data, while only 3 (9.4%) used the WHO Assessment Instrument for Mental Health Systems. The distribution by year shows that there has been constant growth in research on the subject, except for 2018.

As far as the countries studied are concerned, 10 (31.3%) were in Asia (China, Japan, India, Gaza, Iran and Malaysia), 6 (18.8%) in Africa (Ethiopia, Sudan, Tanzania and Kenya), 4 (12.5%) in Europe (Germany and England), 2 (6.3%) in South America (Brazil and South America in general), 2 (6.3%) in North America (Massachusetts and the US) and 2 (6.3%) in Oceania, specifically Australia. In addition, two studies (6.3%) compared different populations and four (12.3%) covered the entire world population. Of the studies carried out on specific populations, 41.7% involved LMICs and 58.3% HMICs.

#### 3.2 | Barriers in mental healthcare systems

Five descriptive categories were found in relation to the challenges and barriers in mental healthcare systems: (a) structural barriers, (b) health culture, (c) illness costs, (d) rehabilitation management, and (e) biomedical model. A sixth category analysed the impact of these barriers and challenges on families as alternative care providers. These categories were divided into a total of 25 subcategories, as shown in Table 3.



**FIGURE 1** PRISMA 2009 flow chart (Moher, Liberati, Tetzlaff, & Altman, 2009)

**TABLE 2** Methodological and quality characteristics of the papers analysed

Author (year)	Country	Study design	Sample	Journal	Database index	JIF	MQ
Abayneh et al. (2017)	Ethiopia <sup>a</sup>	Qualitative	13 users of mental health services, 10 caregivers, 8 heads of public healthcare centres and 8 politicians in charge and service developers	BMC Psychiatry	JCR	2.666	High
Akbari et al. (2019)	Iran <sup>b</sup>	Qualitative	29 service providers and policy makers	Administration and Policy in Mental Health and Mental Health Services Research	JCR	2.681	High
Ali and Agyapong (2016)	Sudan <sup>a</sup>	Mixed-methods	103 caregivers and 6 consultant psychiatrists	BMC Health Services Research	JCR	1.932	Low risk of bias
Ambikile and Iseselo (2017)	Tanzania <sup>a</sup>	Qualitative	7 service providers, 7 people with SMI and 16 caregivers	BMC Psychiatry	JCR	2.666	High
Arandjelovic et al. (2016)	Australia <sup>b</sup>	Review		Australian & New Zealand Journal of Psychiatry	JCR	5.000	High
Athié et al. (2016)	Brazil <sup>b</sup>	Mixed-methods	18 health managers and 24 professionals	BMC Health Services Research	JCR	1.932	Low risk of bias
Azman et al. (2019)	Malaysia <sup>b</sup>	Qualitative	15 family caregivers of people with SMI	International Social Work	JCR	0.603	High
Balhara et al. (2016)	France, Spain, Israel <sup>b</sup> and India <sup>a</sup>	Review		Journal of Dual Diagnosis	JCR	1.338	Moderate
Bee et al. (2015)	All countries	Review		British Journal of Psychiatry	JCR	7.233	High
Bitta et al. (2017)	Kenya <sup>a</sup>	Quantitative	Key components of the Kilifi mental health system	International Journal of Mental Health Systems	JCR	1.986	Low risk of bias
Calvó-Perxas et al. (2018)	Europe <sup>b</sup>	Quantitative	13,507 caregivers of people with SMI from 12 European countries	PLoS One	JCR	2.766	Low risk of bias
Greenfield et al. (2018)	USA <sup>b</sup>	Quantitative	95 caregivers of people with SMI	Journal of Gerontological Social Work	JCR	0.849	Low risk of bias
Hanlon et al. (2017)	Ethiopia <sup>a</sup>	Qualitative	7 service providers and 10 administrators and facility heads	International Journal of Mental Health Systems	JCR	1.986	High
Kaur and Pathak (2017)	India <sup>a</sup>	Review		Economic and Political Weekly	SJR	0.299	Moderate
Keynejad et al. (2016)	All countries	Review		BMC Health Services Research	JCR	1.932	High
Malik and Khan (2016)	Pakistan <sup>a</sup>	Quantitative	Prevalence-based cost-of-illness approach to estimate economic burden of mental illness in Pakistan	Journal of Mental Health Policy and Economics	JCR	0.931	Low risk of bias
Kikuzawa et al. (2019)	Japan <sup>b</sup>	Quantitative	1,800 inhabitants of Japan aged 18–64	Social Science & Medicine	JCR	3.087	Low risk of bias
Kovacs et al. (2018)	Europe	Review		European Psychiatry	JCR	3.941	High
Leng et al. (2019)	China <sup>b</sup>	Quantitative	181 family caregivers of people with SMI	Archives of Psychiatric Nursing	JCR	1.299	Low risk of bias
Mantovani et al. (2017)	African and African Caribbean <sup>a</sup>	Qualitative	14 service providers	Health & Social Care in the Community	JCR	1.573	High

(Continues)

**TABLE 2** (Continued)

Author (year)	Country	Study design	Sample	Journal	Database index	JIF	MQ
Martin et al. (2017)	All countries	Review		International Journal of Social Psychiatry	JCR	1.370	High
Rand et al. (2019)	England <sup>b</sup>	Quantitative	387 caregivers of people with SMI	Health & Social Care in the Community	JCR	1.573	Low risk of bias
Sahithya and Reddy (2018)	India <sup>a</sup>	Review		International Journal of Culture and Mental Health	SJR	0.327	Moderate
Saymah et al. (2015)	Gaza <sup>a</sup>	Mixed-methods	Key components of the Gaza mental health system	International Journal of Mental Health Systems	JCR	1.986	Low risk of bias
Storm et al. (2019)	All countries	Review		Administration and Policy in Mental Health and Mental Health Services Research	JCR	2.681	High
Trapé, Campos, and Costa (2018)	Brazil and Spain <sup>b</sup>	Review		Physis	SJR	0.243	Moderate
Tsui and Tsang (2017)	China <sup>b</sup>	Qualitative	Eight people with SMI and eight caregivers	Psychiatry Research	JCR	2.208	High
Valentini et al. (2016)	Germany <sup>b</sup>	Qualitative	24 caregivers of people with SMI	BMC Psychiatry	JCR	2.666	High
Vigo et al. (2019)	South America	Quantitative	Key components of South America's mental health systems	The Lancet Public Health	SJR	5.493	Low risk of bias
Walter, Yuan, Morocho, & Thekkedath (2019)	USA <sup>b</sup>	Qualitative	18 parents and caregivers of children and adolescents with SMI	Social Work in Mental Health	SJR	0.232	High
Wonders et al. (2019)	Australia <sup>b</sup>	Qualitative	13 users of mental health services aged over 18	Community Mental Health Journal	JCR	1.159	High
Wong et al. (2016)	Japan <sup>b</sup>	Qualitative	Seven mental health social workers	Social Work in Mental Health	SJR	0.232	High

Abbreviations: JCR, Journal Citation Reports; JIF, Journal Impact Factor 2018; MQ, methodological quality; SJR, Scimago Journal and Country Rank.

<sup>a</sup>Low- and middle-income countries.

<sup>b</sup>High- and middle-income countries.



**TABLE 3** Empirical process stemming from the review and subsequent sorting of information into categories and subcategories of analysis

Categories	Subcategories
Structural barriers	Treatment gap
	Weak public health policies and low priority of mental health
	System underfunding
	Weak planning
	Abandonment of the people with mental health problems by the public health system
Health culture	Labelling
	Widespread lack of knowledge about mental illness
	Underuse of services by users
	Use of ritualised practices and alternative “medicines”
Illness costs	Imbalance between GDP per capita and direct care costs per patient
	Treatment costs
	Privatization of care and benefit societies
Rehabilitation management	Shortage and low qualifications of professionals
	Insufficient community resources
	Overcrowding in psychiatric wards
	Discontinuous care
Biomedical model	Worldwide spread of the model
	Prioritization of medicalisation
	Low-impact combined treatments
	Investment in psychiatric macro-institutions
	Subsidiary care
Care provision: families	Overload
	Opportunity costs
	Little social support
	Barriers to family participation

### 3.2.1 | Structural barriers in the creation of healthcare policies

The reviewed studies found structural barriers in the provision of services. These are understood as difficulties deriving from institutional policies and procedures that restrict the rights and opportunities of people with mental illness and their families. In a study carried out in Sudan (Ali & Agyapong, 2016), family caregivers and psychiatrists speak out against the low priority given to mental health when policies are drawn up. Despite the fact that many of the studies analysed report that progress has been made in policies, plans and legislation on mental health (Balhara et al., 2016; Kovacs et al., 2018), an absence of planning and legislation and the development

of inadequate public health policies are frequent and contribute to the stagnation of the system and make it difficult to access treatment (Azman, Jamir, & Sulaiman, 2019; Hanlon et al., 2017; Keynejad et al., 2016). According to Malik and Khan (2016), this lack of will and commitment on the part of the government also affects the drawing-up of specific budgets, which means that the system is underfunded and services are not provided.

The treatment gap is wider in countries with socioeconomic conflicts—war, unemployment, economic recession, unequal distribution of wealth, budget cuts, etc.—regardless of whether they are LMICs or HMICs (Athié et al., 2016; Sahithya & Reddy, 2018; Vigo, Kestel, Pendakur, Thornicroft, & Atun, 2019). In Brazil, even though today it is categorised as an HMIC, mental health is seen as an underfunded area within a system that receives very little federal funding (Trapé et al., 2018). A quantitative study on government spending on mental health in South America reports that the proportion of the health budget allocated to mental health services ranges between just 0.5% and 1.9% in LMICs and 2.4% and 5% in HMICs (Vigo et al., 2019). Nevertheless, budgets and public spending on mental health on a global level tend to be low and ineffective, and government action tends to have little impact or cost-effectiveness, although the impact is more visible in LMICs (Ali & Agyapong, 2016; Ambikile & Iseselo, 2017; Saymah, Tait, & Michail, 2015; Tsui & Tsang, 2017; Trapé et al., 2018).

These structural barriers contribute to the insufficient levels of care, the lack of action taken to deal with current needs and the abandonment of people with mental illness and their families by the public health system. This is denounced in many of the studies analysed as discrimination and a violation of human rights (Abayneh et al., 2017; Ambikile & Iseselo, 2017; Bitta, Kariuki, Chengo, & Newton, 2017; Kaur & Pathak, 2017; Keynejad et al., 2016; Saymah et al., 2015).

### 3.2.2 | Health culture

One of the challenges characterizing mental healthcare worldwide is the labelling and social conception resulting from the fact that mental illness is perceived as stigmatised (Abayneh et al., 2017; Akbari et al., 2019; Ali & Agyapong, 2016; Ambikile & Iseselo, 2017; Arandjelovic et al., 2016; Azman et al., 2019; Bee et al., 2015; Hanlon et al., 2017; Kaur & Pathak, 2017; Keynejad et al., 2016; Kikuzawa et al., 2019; Leng, Xu, Nicholas, Nicholas, & Wang, 2019; Mantovani, Pizzolati, & Gillard, 2017; Vigo et al., 2019; Walter, Yuan, Morocho, & Thekkedath, 2019; Wonders, Honey, & Hancock, 2019). The stigma associated with mental illness conditions the search for help and gives rise to widespread ignorance about the illness, thus acting as a social exclusion mechanism (Mantovani et al., 2017).

The beliefs and attitudes of people when seeking mental healthcare are significant barriers when it comes to using the services. Studies report that, although most people use biomedical models of treatment, patients with mental illness and their families in countries such as India and certain regions of Africa (Ambikile & Iseselo, 2017; Bee, Price, Baker, & Lovell, 2015; Bitta et al., 2017;

Kaur & Pathak, 2017) turn to folk healers and spiritual leaders as the main alternatives to the mental healthcare system to avoid stigmatisation. An investigation carried out in Japan by Kikuzawa et al. (2019) shows that the contextual and cultural setting, the beliefs, experiences, religion and spirituality of the community condition the search for and provision of support due to fear of being rejected by society. The studies analysed also indicate that the lack of knowledge and awareness of mental illnesses leads to people underusing the services, adopting deflective behaviours and contributing to the caregivers' burden (Ambikile & Iseselo, 2017; Bee et al., 2015; Kaur & Pathak, 2017; Kikuzawa et al., 2019). Kaur and Pathak (2017) believe that the definitions of mental illness used in India are out of date and should be reconsidered. Along similar lines, Tsui and Tsang (2017) describe how users and family caregivers in urban and rural areas have no clear understanding of the concepts of psychiatric rehabilitation and recovery and therefore fail to identify the necessary interventions, strategies and techniques designed to satisfy the requirements of people with mental illness.

### 3.2.3 | Illness costs

The study carried out by Kovács et al. (2018) estimates that the average annual medical cost of schizophrenia is 5,800€ per patient in Europe, ranging from 533€ in Ukraine to 13,704€ in the Netherlands. Meanwhile the estimated average cost of mental illnesses in Pakistan is PKR 62,969 (356€) (Malik & Khan, 2016). However, Sahithya and Reddy (2018) point out that it is impossible to estimate real illness costs because the indirect costs of mental disorders (reduction in the labour force, school drop-out rates, spending on social support and the costs associated with consequences such as disability through comorbidity, lack of housing, violence, suicide, caregiver burden, etc.) are higher than the direct costs (treatment, medication, hospitalisation, etc.). Kovács et al. (2018) report that medication costs account for less than 25% of the direct costs of medical care per patient in Europe, while hospitalisation is the largest component of healthcare service costs (40%–90%) in most countries.

The studies analysed make it clear that direct illness costs, defined as the economic burden of mental illnesses, are a challenge to the system. The spending imbalance is negatively associated with real GDP per capita, which disproportionately affects LMICs (Balhara et al., 2016; Malik & Khan, 2016; Sahithya & Reddy, 2018). According to Vigo et al. (2019), spending on mental health in South America is low compared to the illness burden associated with it and is mainly allocated to psychiatric hospitals rather than psychosocial rehabilitation resources. This imbalance makes the treatment gap more noticeable in poorer countries and leads to an increase in private spending on mental health and out-of-pocket expenses for families.

The alarming cost of treatments is another challenge facing public mental healthcare systems. In the studies analysed, the cost of

hospitalisation represents the biggest direct cost for mental health and is unaffordable for families and for the system itself (Kovacs et al., 2018; Malik & Khan, 2016; Sahithya & Reddy, 2018; Tsui & Tsang, 2017). The systematic review carried out by Kovacs et al. (2018) on the direct costs of medical attention for schizophrenia finds that persisting with the pharmacological treatment prescribed and discontinuity of care are predictive factors of hospitalisation and are associated with worse results and higher healthcare costs.

Private-sector spending is an important source of funding for mental health (Balhara et al., 2016; Hanlon et al., 2017; Vigo et al., 2019). A comparative study of France, India, Israel and Spain highlights that 51% of medical services in France and almost a third in Israel are provided through the private system, that in India cover is mainly provided via private psychiatrists, and that in Spain there is an extensive network of private medical services administered by health insurance companies (Balhara et al., 2016). In all cases, private care requires families to pay out-of-pocket expenses for hospital stays, outpatient appointments and medicines. In addition, mental illnesses are not generally covered by private health insurance (Balhara et al., 2016; Saymah et al., 2015), although medicine costs sometimes are (Malik & Khan, 2016; Tsui & Tsang, 2017).

### 3.2.4 | Rehabilitation management

The studies report the existence of barriers to the provision and use of services, and that these contribute to the treatment gap in mental health. They include a lack of human resources, lack of continuity and a shortage of community healthcare services. The investigations analysed agree that there are few professional workers and that those there are lack training or the motivation and incentive conducive to the provision of adequate care (Ambikile & Iseselo, 2017; Arandjelovic et al., 2016; Sahithya & Reddy, 2018; Saymah et al., 2015). A study carried out in Kenya (Bitta et al., 2017) reports that in Kilifi County there are no psychiatrists or psychologists, just two psychiatric nurses for a population of 1.2 million. Tsui and Tsang (2017) warn of the shortage in China of professional rehabilitation workers, including occupational therapists and social workers, since these professionals are not qualified to work in the field of psychiatry. Kaur and Pathak (2017) and Sahithya and Reddy (2018) argue that this shortage is due to the stigmas associated with psychiatry as a discipline and with mental health, which means that this area of healthcare is unpopular and its appearance on the curriculum in faculties of medicine is limited.

Another challenge involves ignorance of the concept and aims of psychiatric rehabilitation and recovery, not to mention the role and importance of community care (Tsui & Tsang, 2017). Hence the shortage of community mental health resources and psychiatric rehabilitation services (Ali & Agyapong, 2016; Leng et al., 2019). Saymah et al. (2015) and Trapé et al. (2018) point to a certain amount of progress being made in mental healthcare reform through the gradual transition towards more community-based services and a reduction in the number of hospital beds. However, the gap in mental health



legislation in support of deinstitutionalisation, the fact that mental health funding is generally directed towards psychiatric hospitals, and an absence of services in many countries all leads to overcrowding in psychiatric wards (Ambikile & Iseselo, 2017; Arandjelovic et al., 2016; Saymah et al., 2015) and an increased care burden for families (Valentini et al., 2016; Wonders et al., 2019). Discontinuity of care is also found to be a barrier in the studies analysed (Athié et al., 2016; Storm, Husebø, Thomas, Elwyn, & Zisman-Ilani, 2019; Valentini et al., 2016) due to long waiting times (Ali & Agyapong, 2016), the limited time allocated for doctors to spend with each patient (Ambikile & Iseselo, 2017), lack of space and infrastructures (Hanlon et al., 2017) and geographical distance (Bee et al., 2015), which prevents many people from using the support resources available.

### 3.2.5 | Maintenance and predominance of the biomedical model

Mental health policies and procedures all over the world are based on a biomedical approach that tends to ignore both the sociocultural factors associated with the appearance of illnesses and the development of treatments that consider a person's psychosocial status (Hanlon et al., 2017; Keynejad et al., 2016; Saymah et al., 2015; Tsui & Tsang, 2017; Wong, Wan, & Ng, 2016). Limited government spending on the development of mental health services biases treatments towards medicalised and institutionalised services (Saymah et al., 2015; Storm et al., 2019). Psychiatric macro-institutions such as hospital wards and homes are important when it comes to looking after people in acute phases of illness who require continuous care and treatment. Nevertheless, authors including Wong et al. (2016) and Hanlon et al. (2017) maintain that the problem stems from accepting the biomedical model as the only one possible and assigning a subsidiary role to psychosocial care.

Kaur and Pathak (2017) report that mental health in India is considered just like any other illness. They argue that the politicians in charge should be aware of the characteristics of these disorders and that ideally they should be dealt with differently from other illnesses. The maintenance and predominance of the biomedical model in mental health helps lead to a constant, bureaucratized and systematic dehumanisation on the part of the system in its dealings with people and makes it difficult to implement combined treatments for the sick person and their family (Akbari et al., 2019; Ambikile & Iseselo, 2017). People with mental illness drift from one psychiatric institution to another in the hope of finding the right pharmacological treatment, instead of there being integrated interventions that enable them to be accompanied throughout the process and that believe in the person's recovery (Bee et al., 2015; Walter et al., 2019).

One of the barriers most frequently analysed and condemned by the studies we selected is the decentralisation of mental health services and the need for them to be integrated into primary healthcare (Abayneh et al., 2017; Athié et al., 2016; Hanlon et al., 2017; Kaur & Pathak, 2017; Malik & Khan, 2016; Saymah et al., 2015; Walter

et al., 2019). According to a study carried out in Brazil by Athié et al. (2016), healthcare managers and professionals believe that incorporating mental health into primary healthcare is a requirement of the system, despite the limitations that exist as regards institutional processes, human resources and knowledge of mental health. Many countries have attempted to join forces in order to integrate mental health services into all other healthcare services, but accessibility is currently considered inadequate (Kaur & Pathak, 2017; Saymah et al., 2015). Finally, the investigation by Walter et al. (2019) notes that paediatric services rarely include mental health in primary healthcare services for children.

### 3.2.6 | Alternative care provisions: the family as a resource

The last analysis category concerns the use of the family as the main care provider due to the deficiencies of the mental health system (Abayneh et al., 2017; Akbari et al., 2019; Azman et al., 2019; Calvo-Perxas et al., 2018; Greenfield, Hasche, Bell, & Johnson, 2018; Leng et al., 2019; Rand, Malley, & Forder, 2019; Sahithya & Reddy, 2018; Valentini et al., 2016; Wong et al., 2016). Wong et al. (2016) argue that living in a country of family-based care has a significant effect on family caregivers' health. Opportunity costs along with economic costs, unemployment, symptoms and treatment, emotional stress resulting from discrimination, social isolation, stigma, disability and even poverty are some of the factors that contribute to caregiver overload (Sahithya & Reddy, 2018). A study involving 387 informal and mainly family caregivers in England identifies the perceived unavailability or unsuitability of other sources of care, the time needed to provide care, the skill or capacity to care and the satisfaction involved in providing care as factors conditioning their quality of life (Rand et al., 2019). An investigation carried out in 12 European countries by Calvo-Perxas et al. (2018) stresses that policies of non-financial support aimed at family caregivers (education, training, family respite services, counselling, etc.) have a greater protective impact on caregivers' health than financial support measures, plus an indirect effect on the health of the people with mental illness receiving the care.

Despite the fact that family-centred care is recognised as being one of the best care methods as regards mental health, the studies agree that there is a lack of support from public healthcare systems (Azman et al., 2019; Leng et al., 2019; Mantovani et al., 2017; Storm et al., 2019; Tsui & Tsang, 2017). Valentini et al. (2016) argue that interventions based on providing support to caregivers have a positive impact on the psychological health of family members and users and leads to a reduction in the care burden. They believe that these interventions should form part of the mental healthcare services. Along similar lines, Wonders et al. (2019) add that including the family in the user's treatment and recovery process should be one of the pillars of mental healthcare policies, but so far this has not been the case in practice. According to Martin, Ridley, and Gillieatt (2017), this is due to the exclusion, disempowerment and invisibilisation of families on the part of governments.

The studies show that cultural familism that sees the family as a cohesive unit whose members all depend on each other continues to be the basic pillar underpinning social policies in many countries (Leng et al., 2019; Storm et al., 2019; Tsui & Tsang, 2017). Leng et al. (2019) claim that the underfunding of the system and structural procedures in mental healthcare in China limit formal and financial support for family caregivers. A lack of information and barriers that prevent families from participating in decision-making, non-adherence to pharmacological treatments, barriers impeding access to resources, communication gaps and a lack of continuity in care all show that governments are incapable of guaranteeing healthcare to people with mental illness in the community and force families to become the principal support (Azman et al., 2019; Martin et al., 2017; Storm et al., 2019; Tsui & Tsang, 2017; Walter et al., 2019; Wonders et al., 2019).

## 4 | DISCUSSION

This study has reviewed the scientific literature and identified 32 research articles focusing on challenges and barriers in mental healthcare systems and their impact on the family. Our analysis provides evidence of the deficiencies and limitations of institutional policies and procedures that restrict access to treatment for people with mental illness. Despite evidence from the literature regarding system shortcomings and the efforts made by the politicians in charge, the review highlights the fact that mental healthcare systems all over the world are still in a process of development and have yet to reach the quality indicators set by the WHO (2010).

Previous studies have reported that mental disorders represent a growing illness burden in LMICs and that these countries lack the means to cope with such a burden (Chisholm et al., 2007; Petersen, Lund, & Stein, 2011; Steel et al., 2014). The results of the present investigation show that this problem has been explored in the literature at a global level, both in LMICs (especially in African and Asian countries) and HMICs (mainly in European countries). As regards the year of publication, our study shows that in recent years there has been an upward trend in the analysis of healthcare systems as a research priority for political action on mental health. Authors such as Haro et al. (2014) and Peltzer-Jones et al. (2019) have stressed the need to investigate the effectiveness of the policies carried out in different public healthcare systems and to address the quality of the care in order to develop feasible action plans to tackle limitations. In addition, although the studies meet the quality standards set by the scientific community, there is great heterogeneity in their aims and data-collection techniques, and this increases the risk of bias and the capacity to extract conclusions from the results (Higgins et al., 2011; Singh, 2013; Walsh & Downe, 2006). Such methodological characteristics suggest that there may be a need to extend the empirical corpus and design instruments and techniques to evaluate healthcare systems along with their possible improvements, as indicated by the WHO (2005).

The qualitative data analysis identified the presence of a host of structural, cultural, economic and treatment barriers that impair the quality of life not only of people with mental illness but of their family members too. These barriers include underfunding, an absence of legislation, weak planning, lack of knowledge about the illness and lack of community and rehabilitation resources. Most of the investigations mention the high cost of mental healthcare and the need to reduce it. However, as Ruiz-Rodríguez et al. (2017) point out, there are many other incalculable costs that are not taken into account when it comes to quantifying the economic burden of the illness. These include the costs to people with mental illness and their family members in terms of lost social and employment opportunities. The results of the present investigation show that such challenges and barriers in mental healthcare systems are more visible and more alarming in LMICs, although healthcare models that are inefficient and inaccessible can also be found in HMICs (Fiskin, Miglani, & Buzza, 2018).

Like in other investigations (Pescosolido, 2019; Saxena, Kane, Krawczyk, & Bass, 2019), this study's findings suggest that the stigma associated with mental illness is firmly established in all social structures and acts as the main limiting factor for the creation and development of policies to guarantee the well-being of this collective. The treatment gap in mental health is therefore no more than a reflection of the historical unfairness of the position given to it on the political agenda compared to other illnesses (Murphy et al., 2019; Votruba & Thornicroft, 2016). Given these challenges, the studies analysed show that the family is the underlying resource used to cover the system's weaknesses, taking on the task of continuous care and the costs that this implies in order to ensure its biopsychosocial well-being.

As the investigations by Semrau et al. (2016) and Carbonell and Navarro-Pérez (2019) conclude, the fact that families make up for the lack of public health resources is a latent challenge that should be met by creating real integrated care policies following a holistic approach that includes the participation of people with mental illness and their family caregivers. Despite the fact that none of the included studies tested the efficacy of interventions aimed at providing support for family members looking after people with a mental health condition, the study by Weiss, Hadas-Lidor, Weizman, and Sachs (2018) showed that there is a need to develop and implement family interventions based on the evidence of mental health being a public health priority and to encourage family caregivers to participate in these interventions from the earliest stages of the mental illness.

In line with the Mental Health Consumer/Survivor Movement, the results of this study indicate that, in order to guarantee the human rights of those with mental illness and their families, mental illness policies and practices all over the world need to be reformed and the predominant biomedical and pharmacological model needs to be overturned. As Davidson (2016) points out, a crucial element for the transformation and improvement of mental health everywhere is knowledge and understanding, a return to and implementation of practices aimed at the recovery, well-being

and full integration of the person with mental illness into the community.

In line with the recommendation in Forsman et al. (2015), this study's findings indicate that there is a need to evaluate mental health worldwide and analyse the real sociocultural and socio-economic contexts and requirements of each country. All mental healthcare systems should therefore be rigorously assessed using the same instrument of analysis adapted to each context. However, the key role in improving mental healthcare systems will need to be taken by governments, which should be made aware of the impact of today's austere care policies and the way they infringe human rights. In order to meet this challenge, as Gil-Rivas, Handrup, Tanner, and Walker (2019) and Thornicroft, Deb, and Henderson (2016) have already pointed out, mental health must move to the top of the political agenda so as to guarantee adequate funding for the planning, development and evaluation of the services and to reduce the stigma and discrimination suffered by people with mental illness.

#### 4.1 | Limitations of the study

This review has a number of limitations. The list of search keywords may not be sufficiently comprehensive to achieve an exhaustive search. Publication bias could also have been a limitation. The searches may have omitted relevant results from other studies due to the inclusion requirement for scientific papers and articles to have been published in indexed journals with impact factors, or from unpublished studies with non-significant or "negative" results.

Three additional limitations were found that could not be dealt with in the study. First, the literature is unable to quantify the costs of mental illness in real terms, and neither can it quantify the real costs to families in terms of opportunity costs, giving up work, reducing social relations, etc. Second, the literature lacks a perspective that focuses on treatment and recovery in mental health which is aimed at a person's recovery over the long-term. And third, the results may have focused on acute mental health in particular.

## 5 | CONCLUSIONS

Overcoming the barriers in mental healthcare systems is a challenge for politicians all over the world. Mental health requires a real change away from today's biomedical and pharmacological model to one that can guarantee the recovery, care and well-being of everybody involved. Our systematic integrative review highlights the burden taken on by families due to the shortcomings of mental healthcare systems and has shown the importance of integrating mental health at primary healthcare level and fighting to reduce the stigma of mental health in all areas. It has also shown how important it is for the person with mental illness and their family members to participate in the treatment process and

in developing policies to help strengthen the mental healthcare system by improving the adaptation, continuity, suitability and efficiency of the care, providing higher quality resources and instilling more positive attitudes in service providers.

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#### CONFLICT OF INTERESTS

The authors declare that they have no conflicts of interest.

#### ORCID

Ángela Carbonell  <https://orcid.org/0000-0003-2180-4123>

José-Javier Navarro-Pérez  <https://orcid.org/0000-0001-6363-7154>

Maria-Vicenta Mestre  <https://orcid.org/0000-0003-2842-0202>

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