
The care crisis in Spain: an analysis of the family care situation in mental health from a professional psychosocial perspective

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

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

*Department of Social Work & Social Services
Universitat de Valencia (Spain)*

Versión Aceptada:

Carbonell, A. & Navarro-Pérez, J.J. (2019) The care crisis in Spain: an analysis of the family care situation in mental health from a professional psychosocial perspective, *Social Work in Mental Health*, <https://doi.org/10.1080/15332985.2019.1668904>

The care crisis in Spain: an analysis of the family care situation in mental health from a professional psychosocial perspective

Ángela Carbonell Marqués, MSW and José Javier Navarro-Pérez, PhD

Social Work and Social Services Department, University of Valencia (Spain), Valencia, Spain

ABSTRACT

The aim of this article is to investigate the importance of family care in mental health and identify the shortcomings of the Spanish model of health care for the mentally ill. The empirical process comprised three qualitative procedures involving 37 experts from different regions of Spain. In order to guarantee the rigor of the data, a social worker discussion group was set up to create an interview script. Interviews were then carried out with 22 professionals who take care of people with mental illness in various public facilities throughout the country. A second focal group met three times to validate the categorizations analyzed in the interviews. The results of the empirical process indicate a need to remodel the mental health care system, which can be described with reference to five critical characteristics: 1) a lack of financial and human resources for mental health, 2) a lack of effective coordination among all the institutions and authorities involved, 3) a lack of quality resources aimed at rehabilitation and social reintegration as alternatives to institutionalization, 4) a lack of integrated care, and 5) a lack of a common healthcare framework for all professional workers in all the regions. A remodeling of the system is necessary to enable the rehabilitation, recovery, empowerment and development of people with SMD and thus ease the burden and improve the quality of life of family caregivers.

KEYWORDS

Mental health; caregiver; health care model; overload; social work; focus groups; interviews

Introduction

Psychiatric reform in Spain began to be rolled out after the passing of the Health Act (The General Health Law) of 1986 and the incorporation of mental and social components into the concept of health (World Health Organization [WHO], 2017). Mental health started to become as much of a priority in Spain as in other European countries (Mental Health Declaration for Europe, 2005), the aim being to promote mental health and prevent mental disorders by guaranteeing a coordinated public network of resources as part of the health system (Ahmed, Bruce, & Jurcik, 2018; Forsman et al., 2015). However, the deficiencies of these resources and the underfunding and precariousness of mental health compared to other health services has led to the overmedicalization of psychiatric clients to make up for the lack of care resources (Jiménez, 2011) and the transfer of public

CONTACT Ángela Carbonell Marqués  angela.carbonell@uv.es  Social Work and Social Services Department, University of Valencia (Spain), Tarongers Avenue, 4B, Valencia 46022, Valencia

health system responsibilities to the families, who adopt an active role in caring for the person with mental illness that is not open to appeal (Gomes & Dos Santos, 2016). Deinstitutionalization has therefore always meant a lower quality of life for caregivers because of the impact it has on their lives (Guedes, Pereira, & Chaves, 2017) due to the ever-growing number of responsibilities they have to take on and the subsequent deresponsibilization of the state (Soto, Espinosa, Vega, & Vega, 2012).

The notion of a “care crisis” is evident in the social and political inability of states to provide for the care and welfare of their members (León, 2014). As Stein, Gonzalez, Cupito, Kiang, and Supple (2015) points out, social protection as far as Mediterranean welfare models are concerned is still in development. It is common practice to rely on *familism* – a cultural value referring to the importance of strong family loyalty – to channel and mitigate the state’s deficiencies in economic and social policies (León & Pavolini, 2014; Saraceno, 2016), with women left to assume the role of main caregivers following established gender roles, accepting and suffering the consequences of the task. The Spanish government’s cost-containment policies and the underdevelopment of public care services have led to a reprivatization of care in households (Guillén, González, & Luque, 2016), the casualization of family caregivers and a new burden for families and especially for women to carry (Mosca, Van der Wees, Mot, Wammes, & Jeurissen, 2017; Peña-Longobardo, Oliva-Moreno, García-Armesto, & Hernández-Quevedo, 2016).

Severe mental disorder (henceforth SMD) is described as a predictor of dependence risk due to functional alterations, the persistence of symptoms and restrictions in activity and social participation together with the complexity that characterizes these illnesses and the way they affect different areas of life (Aylaz & Yıldız, 2018). Those with serious mental health problems are defined as a population likely to need long-term care and assistance (Alexander et al., 2016). The scientific literature is rich in studies (Jagannathan, Thirthalli, Hamza, Nagendra, & Gangadhar, 2014; Krishnan & Sood, 2017; Navarro-Pérez & Carbonell, 2018) that analyze the impact that this care has on families and the way this is associated with a lower quality of life (Narasipuram & Kasimahanti, 2012). Despite the fact that it is becoming more and more widely recognized that it is not only associated with negative consequences but also with subjective gains and satisfaction (Kulhara, Kate, Grover, & Nehra, 2012), care is a great devourer of time and opportunity in many areas of life.

Dockery et al. (2015) point out that structural barriers play an important role as far as caregivers are concerned. The high costs of the illness (medical treatment, pharmacological treatment, etc.), limited access to resources (inadequate ambulance services, lack of hospital beds) and the financial cost of specialist mental healthcare mean that neither caregivers nor patients receive the care they need. As Hong and Casado (2015) show, these barriers lead to deficient healthcare and cause people with mental health issues to abandon treatment and give up regular

use of the mental health services. The effect of this is to increase the caregivers' burden and intensify the patients' symptoms (Akbari, Alavi, Irajpour, & Maghsoudi, 2018).

The biopsychosocial model proposed by Engel (1977) emphasizes the family's influence on the person with mental illness and how the illness affects and modifies family dynamics, making it clear that intervention should involve not only those suffering from a mental illness but also their family members (Shea, 2016). In Spain, health care and follow-up for people with SMD is the job of multidisciplinary teams composed of psychiatrists, psychologists, social workers and nurses. However, the development of care protection programmes for mental health caregivers are the responsibility of experts in social work, both as regards public health and the provision of services by third-sector providers and other private bodies. The duties of the social worker are to support and accompany the families, and thus they become the families' go-to professional (Martín, 2013).

Although previous papers have carried out detailed analyses of the impact of caring for a person with mental illness – mainly schizophrenia (Gopal et al., 2017; Kumar, Suresha, Thirthalli, Arunachala, & Gangadhar, 2015; Kung, 2016) – on all areas of the caregiver's life (Gater et al., 2014), few studies have included the peculiarities of public health care models and their contextual and structural limitations in dealing with the care crisis. The present study therefore has two main objectives: 1) to identify study variables in order to find out the extent of family care responsibility in mental health, and 2) to explore the structural barriers of the mental healthcare model from a professional psychosocial perspective.

Method

An exploratory descriptive qualitative study was carried out which, through the use of discourse analysis, would allow an interpretative analysis of professional experiences, opinions, expectations and perceptions of the mental health care system in Spain. The investigation is based on a qualitative approach and uses three different procedures and techniques. The total sample was made up of 37 professionals specializing in mental health from a variety of Spanish regions (See Table 1).

Procedures

The first procedure involved a focus group (FG1) that produced the interview script. This group was made up of experts whose objective, given the regional nature of the existing scientific literature, was to identify new variables and decide on the indicators needed to design an interview that would make it possible to thoroughly explore the extent of family care responsibility in mental health and

Table 1. Methodological design of the study.

Technique	Objective	Sample	Inclusion criteria
Group of experts 1	To identify study variables To develop an interview script for data collection.	Eight social workers who look after people with SMD and their family members	<ul style="list-style-type: none"> – Social workers – Direct care of people with mental illness and their family members in public mental health facilities – More than six years' professional experience in the sector
Interviews with professionals	To find out how mental health professionals perceive family care and the shortfalls in the mental health care model	22 professionals in frequent contact with family members	<ul style="list-style-type: none"> – Professional profiles that form part of multidisciplinary teams in mental health: psychologists, psychiatrists, social workers and nurses. – Six years' professional experience in the sector – Direct care of people with mental illness and their family members in public mental health facilities
Group of experts 2	To verify or refute the categories obtained from the analysis of the interviews	Seven skilled professionals in management positions	<ul style="list-style-type: none"> – Professionals occupying management positions in public mental health services – Managers in charge of other professionals – More than 10 years' professional experience in the post

identify structural barriers in the public mental healthcare model. FG1 comprised eight social workers with jobs in different public mental health facilities (public health system, NGOs, centers for the rehabilitation and reintegration into the community of people with SMD, mental health professionals, and psychiatric rehabilitation unit workers) and at least six years' experience in the sector. The group dealt with a number of different areas: informal care and its consequences, the care of people with SMD, models of public health care and future interviews with social work professionals. When the group had completed its task, the content was transcribed and checked. The interview script was produced following the indicators proposed, focusing on those areas the experts suggested as a guideline for the interviews: 1) informal care in Spain, 2) caregiver overload, 3) the characteristics of caring for someone with SMD, 4) intervention with families, and 5) the public health care model.

Once the command sequence had been designed, the second procedure involved carrying out in-depth interviews using the interview script. 22 people were the subject of these interviews, which were conducted in such a way as to include the different professional profiles that make up the multidisciplinary mental health teams: psychologists, psychiatrists, social workers and nurses. Information saturation was reached after 22 semi-structured interviews with these professionals, following gender parity criteria. Most of the quotes in the Results section were obtained from this source.

The third procedure involved another focus group (FG2) that was set up to validate the process used to categorize the information obtained from the interviews and to discuss the results. It was made up of seven skilled professionals occupying management positions in mental health services, all of whom had at least ten years' experience in the sector (heads of service, representatives of professional associations, members of mental health committees, and trade union representatives in areas of community health). To validate the categorizations analyzed in the interviews, FG2 met for three sessions, ratifying or refuting the categorizations and the quality of the information derived from the interviews.

Two (PhD) researchers/social workers (AC and JJNP) with special training in the subject led and developed the techniques applied in the study, while a third person was on hand to assist where necessary.

Data collection

Authorization to contact these different experts was sought from the relevant authorities. The department dealing with mental health matters supplied us with a list of 398 eligible mental health workers who satisfied the inclusion criteria shown in Table 2. Once authorization had been granted by the autonomous administrations in all regions of the country, emails were sent to each of the professionals and the study's aims were explained to the potential participants and the research team introduced.

Table 2. Description of the study's participants.

Code	Technique	Occupation	Sex	Experience	Region
SW1	Focus group 1	Social worker	Female	8 years	Madrid
SW2	Focus group 1	Social worker	Male	12 years	Galicia
SW3	Focus group 1	Social worker	Female	11 years	Galicia
SW4	Focus group 1	Social worker	Female	23 years	Aragon
SW5	Focus group 1	Social worker	Female	6 years	Catalonia
SW6	Focus group 1	Social worker	Male	8 years	Valencian Com.
SW7	Focus group 1	Social worker	Male	13 years	Murcia Region
SW8	Focus group 1	Social worker	Male	15 years	Valencian Com.
FC1	Interviews	Psychiatrist	Female	16 years	Andalusia
FC2	Interviews	Psychiatrist	Female	6 years	Madrid
FC3	Interviews	Psychiatrist	Male	11 years	Asturias
FC4	Interviews	Psychiatrist	Male	17 years	Catalonia
FC5	Interviews	Psychiatrist	Female	15 years	Aragon
FC6	Interviews	Clinical psychologist	Male	6 years	Castile-Leon
FC7	Interviews	Clinical psychologist	Female	7 years	Valencian Com.
FC8	Interviews	Clinical psychologist	Male	9 years	Canary Islands
FC9	Interviews	Clinical psychologist	Male	24 years	Castile-La Mancha
FC10	Interviews	Social worker	Male	32 years	Andalusia
FC11	Interviews	Social worker	Female	6 years	Andalusia
FC12	Interviews	Social worker	Male	8 years	Madrid
FC14	Interviews	Social worker	Male	15 years	Balearic Islands
FC15	Interviews	Social worker	Female	13 years	Extremadura
FC16	Interviews	Nurse	Male	15 years	Madrid
FC17	Interviews	Nurse	Male	7 years	Catalonia
FC18	Interviews	Nurse	Female	27 years	Cantabria
FC19	Interviews	Nurse	Female	26 years	Catalonia
FC20	Interviews	Nurse	Female	14 years	La Rioja
FC21	Interviews	Assistant nurse	Female	12 years	Valencian Com.
FC22	Interviews	Assistant nurse	Male	26 years	Murcia Region
EX1	Focus group 2	Social worker	Female	11 years	Catalonia
EX2	Focus group 2	Social worker	Male	29 years	Navarre
EX3	Focus group 2	Social worker	Male	16 years	Basque Country
EX4	Focus group 2	Social worker	Female	21 years	Madrid
EX5	Focus group 2	Clinical psychologist	Female	11 years	Castile-La Mancha
EX6	Focus group 2	Clinical psychologist	Female	22 years	Aragon
EX7	Focus group 2	Nurse	Male	21 years	Basque Country

A total of 398 possible participants from all the autonomous regions of the country were contacted. 57 (14.3%) did not agree to participate and 192 (48.24%) did not reply to the invitation. Thus a total of 149 (37.44%) agreed to take part in the study and were assigned specifically to one of the three procedures according to their professional profile and job and their number of years' experience in the sector. Once the lists of participants in each process had been compiled, a stratified selection was carried out on the basis of autonomous region and sex in order to ensure that all regions were represented and to guarantee gender parity. Finally, a total of 37 participants covering all 17 autonomous regions of Spain were identified. The regions with greater population had greater representation in the sample interviewed.

Interviews and focus group meetings were conducted in person in the Social Sciences Laboratory of Social Sciences (University of Valencia, Spain). The

opinions expressed and information supplied in the interviews and focus groups were collected via video and audio recording. All informants gave written informed consent for the study and requested a copy of the interview report. Skype software was used to connect the experts with the focus groups when face-to-face meetings were impossible due to the nationwide nature of the study.

Free, prior and informed consent was secured from the 37 participants of the study. The investigation complied with national (Law 14/2007 of 3 July on Biomedical Research) and international standards in research ethics. Study protocols met all ethical standards as required by the Code of Ethics of Social Workers in Spain (2012) and Organic Law 15/1999 of 13 December on the Protection of Personal Data. All research procedures were approved by the Committee for Ethics and Experimental Research of a large university in Spain.

Data analysis

The empirical procedure was rigorous and adhered to objectivity standards for qualitative investigations. Deductive content analysis was used to obtain data from the interviews and focal groups. To obtain the results the interviews were transcribed, and an open categorization process carried out, the purpose of which, following Coffey and Atkinson (2003), was to break down the data and group them into different areas and categories that shared the same unit of meaning. Coding was applied to lines or fragments of discourse that contained relevant information. With two researchers/social workers (AC and JJNP) working first individually and then together, a code manual was compiled to organize and establish connections between categories using the consolidated criteria for reporting qualitative research: COREQ (Tong, Sainsbury, & Craig, 2007). In case of disagreements between coders, a third researcher (MVM) was on hand to review any issue when necessary. COREQ is a checklist of 32 items grouped into three domains: (I) research team and reflexivity, (II) study design and (III) findings, data analysis and research report. It is therefore a useful tool for the empirical process and was completed by all the researchers so as to provide information on important aspects of the research team, the study methods and context, and the results along with their analysis and interpretation. This manual was constantly being modified as the data were interpreted in order to assist in the organizational process and establish solid relationships between categories.

The interaction effect of the focus groups allowed intra-method triangulation to be carried out, whereby the FG1 and FG2 results gave greater depth and strength to the interview results. This methodological triangulation meant that different data-collection methods and techniques could be combined to get closer to the object of study, achieving greater precision than if only a single technique had been applied (Denzin, 1970). It also made it possible to view the subject of investigation from different angles and

professional perspectives, thereby increasing the validity and consistency of the findings.

MAXQDA 12 computer software was selected for the analysis, assisting in the task of reducing or simplifying the data obtained during an investigation based on a qualitative paradigm (Saldaña, 2015).

Findings

The results from the methodological triangulation of the focus groups and in-depth interviews were collected. The coding process established five main categories for the object of study, which were then subdivided into a total of 20 subcategories depending on the participants' discourses (See Table 3). Bearing in mind the aims of the present study, an analysis was carried out of those categories that involved the mental health care system: informal care and the public health care model.

Informal care in the mediterranean welfare model

The family as part of the welfare protection system

In Spain the family was described as an important pillar of society making up for the shortcomings of the welfare state. Participants referred especially to the existence of a care culture in which it is normally the family that takes on the responsibility of caring for people who are in some way limited in their capabilities:

“Informal care is extremely hypertrophied because what it does is cover care that should be provided by the public health service and other bodies” (EX2)

“In Spain the family tends to take on the caring role because of the system's deficiencies and lack of support” (FC21)

The situation with informal care was described by the professionals from two perspectives. On the one hand it is seen as something negative because it is the

Table 3. Empirical process stemming from interviews and subsequent sorting of information into categories and subcategories of analysis.

Categories	Subcategories
Informal care	Familism, feminization of care, overprotection.
Caregiver overload	Objective load: loss of time, alteration of social relations, increased effort and responsibilities, effects on physical health, loss of financial capacity. Subjective load: stress, emotional exhaustion, incompetence.
Characteristics of caring for someone with SMD	Uncertainty and worry about the future, obligation to care, guilt, illness awareness, mental health problems, stigma, sociodemographic and clinical variables of caregiver and the person with mental illness.
Intervention with families	Family involvement, mutual help groups, psychoeducational workshops and talks.
Public health care model	Lack of resources, state support, coordination with primary health care, integrated care.

families that have to cover the state's shortcomings, which means an extra burden for them, while on the other it is seen as something positive because this family support and involvement actually exists, whereas there are many countries in which it does not. The negative point of view argues that the family is being exploited by the welfare protection system because of the state's deficiencies, and the state, rather than cover these deficiencies, takes unfair advantage of family values to keep costs down. The participants pointed out that families, especially in mental health, are the people most overlooked by the system:

"The savings the public health system makes by using the families of the mentally ill, if we compare them with spending in other countries, they're huge, thousands of millions". (FC13)

The feminization of care

Experts and participants described the nuclear family of those with SMD as being a mother doing all the caring, an absent father and siblings playing a passive role. Such family dynamics can lead to the incapacitation, infantilization and even invalidation of the person with mental illness and the limitation of their autonomy and capabilities. All the participants also believed that care is generally speaking a task that has been and continues to be associated with women, and that women are those most adversely affected by informal care and everything it entails, such as having to give up work.

"It's usually female care, which means the extra load is taken on solely and exclusively by a woman. She has to leave her job, give up her daily routine to look after someone else, try to fit her life around it". (SW8)

"If someone in the family falls ill, the woman assumes it's going to be her job to look after them". (FC12)

The vulnerabilities of the public mental health care system

Lack of public resources

Following on from the first area of analysis – the importance of family in Spain – participants spoke of the lack of resources allocated to meeting the needs of people with SMD and again reported that families were having to take charge of covering the deficiencies of the public health system, resulting in savings for the state and expenses being transferred to the families.

"Mental health continues to be the ugly duckling of the health system. There's no money spent on it. The money goes to cancer, HIV, the elderly and so on". (FC1)

"Psychiatry's the most neglected part of the system. We took the clients out of the mental hospitals ... but what for? To save money and have their mothers look after them at home". (SW4)

On the subject of the system's deficiencies, participants highlight the lack of public resources aimed at people with SMD. Similarly, it was generally felt that funding should be found for resources tailored to the real needs of the population, i.e. intermediate facilities or alternatives to institutionalization such as sheltered housing, socio-occupational reintegration resources, medium-stay units and rehabilitation centers.

"What's needed is for the services to be adjusted to real needs, but what actually happens is we adjust the clients to the resources we've got, trying to make them fit". (FC6)

A fictitious rehabilitation

Participants stressed that there was an absence of coordination between the social services and health services as regards mental health, and a loss of idiosyncrasy in some of the existing resources. Although the purpose of rehabilitation and social integration centers (CRIS in Spanish) is to facilitate the reintegration of the person with SMD into society, the experts explained that these facilities function as resources which people stagnate in or pass through rather than places that help them to acquire or recover the abilities and skills needed to live a normal life. They also pointed out that resources like the special centers for people with mental illness (CEEM in Spanish), which are meant to improve personal autonomy and provide support for community integration, function as long-term residential centers where people stay until they die, often overmedicalized. This happens especially with SMD sufferers who are disabled.

"(...) the CRIS, the sheltered housing and the CEEMS end up being scrap heaps, not places where you get treatment, improve, recover and leave". (FC18)

"People are locked up just the same, drugged to the eyeballs to keep them quiet, which means we've made the psychiatric model worse than it was before". (EX7)

The experts also describe how in recent years there has been an increase in the number of requests to declare people with SMD unfit to manage their own affairs. The lack of public resources makes this procedure the fastest way of guaranteeing care for people in an institution when their parents die, or they are very old and have nobody to look after them.

"It's a natural care network that absorbs the lack of a public network. Well, in fact there is no public network. When there's no natural care network or informal care either, what happens? We go back to institutionalization and incapacitation as a solution". (SW8)

Lack of professionals and lack of mental health specialization

Participants also mention the lack of health personnel in this area. Together with the pressure under which the system operates, this means there is no

proper continuity of treatment and no immediacy of care, which leads to the aggravation of episodes of acute crisis or situations of family breakdown.

“There’s a lack of professionals because good professionals who are involved and rehabilitate do exist. The main need is recruitment of more specialist health professionals with perhaps more specific training in these subjects, in intermediate or community resources, who’d be able to work with them”. (FC5)

Participants referred to the fact that it is impossible to intervene with families in public mental health facilities due to lack of time, trained workers and resources.

“(…) we do work with clients’ families here, but definitely less than we should”. (FC14)

Lack of a common care framework

Another important aspect is the lack of a common framework to guide the actions of all the various professionals who deal with people with SMD and their families. As the experts point out, the public mental health care system has no real guidelines that provide an overview and set out possible actions that can be taken in the course of professional practice, and this limits the steps that can be taken when dealing with this collective.

“There’s no plan or model (…) we’re in a profession in which we all have our own ways of understanding what’s happening (…) all models are equally valid, so each of us can consider things in whatever way we want and take whatever action we want. What’s more, we all think we’re doing the right thing”. (FC10)

“The way this health care system is structured, it’s really difficult if there’s no model telling you what to do or what path to follow”. (EX5)

Lack of state support

There was a widespread belief that caregivers should feel they have social support to avoid the negative repercussions of the work they do, and this support should also be provided by the state and the relevant authorities. It should consist of economic support and the resources to give caregivers a breathing space, respite, and financial contributions so all the care costs can be met. Apart from the general lack of alternative resources available to this collective, the participants also highlighted the fact that there are no provisions for respite care for families, which would guarantee caregivers a break at times of overload.

“I’m talking about financial support if you’ve left your job, someone to stay with your family member if you can’t, give you a break so you can go away, encourage you to lead your own life, give a boost to your own resources, for the person and their family to be validated and empowered so that life together can be better”. (FC22)

“Spaces need to be provided where the patient can go and live, so the family doesn’t have to look after them”. (SW2).

Objective: a truly integrated service

One of the weak points of the mental health care system is the fact that it is not an integrated service. An analysis of the participants’ discourses shows that an integrated service is defined as a biopsychosocial care model aimed at people with SMD and all their surroundings, mainly their families. The lack of such a model also affects the degree of overload felt by those in the role of caregiver, since the care is centered only on the causes and treatment of the mental illness and not on the consequences it has on the surrounding environment. Other ways of looking at things need to be introduced that would work with all the family and the person with mental illness, with intervention being impossible to consider without all the members of the family, since the illness affects them all and the family plays an important role in the treatment and recovery process.

Integrated attention needs to involve all the professionals on the team and requires coordination with primary health care to avoid situations which lead to family breakdown. The experts admitted that there is no real coordination or teamwork in the multidisciplinary mental health teams when it comes to taking care of the family. This is a service normally provided by social work professionals.

“All the professionals of a unit should look after the families, not just us”. (FC13)

“As social workers we need to know the patient and family’s situation, assess whether the mother is suffering from caregiver overload, advise her and make her a participant in the whole illness process”. (SW1)

It was also believed that a model needed to be adopted that moved away from the medical model of the illness and paid equal attention to all three spheres of the person – biological, psychological and social – with a diversification of the professionals forming part of the process. This comprehensive care model should be combined with educational, health, social and housing resources, for example, to guarantee the welfare of the person with mental illness and their family. The experts stressed there was an absence of coordination among the pillars supporting the welfare state:

“(…) it calls for collaboration in employment, in education, in justice and housing (….) and resources should be created for the mentally ill to cover everything they need”. (EX4)

Discussion

The aim of the present paper was to investigate the importance of family care in mental health and identify the shortcomings of the Spanish model of mental health care from a psychosocial professional perspective.

The results show that the family has become the main source of care for people with SMD, in line with contributions by Naldini, Pavolini, and Solera (2016) and Martin (2015), who agree on the importance of the role played by the family in the Mediterranean welfare model due to the underdevelopment of the public health care services. Participants saw this as both positive and negative. On the one hand they underlined the fact that family support was something that other countries lacked, while on the other they drew attention to the negative impact that providing this care has on the family (Stanley, Balakrishnan, & Ilangovan, 2017).

As other studies have pointed out (Revenson et al., 2016; Vaquiro & Stiepovich, 2010), the task of caring continues to be associated with women due to sociocultural considerations based on role distribution and gender stereotypes. As far as mental health is concerned, the caregiver profile is mainly feminized and elderly, since it often involves mothers who are looking after their children with SMD after giving up their work and social relations. The participants pointed out the inequality in caregiving which, being mainly taken on by women, makes them vulnerable to the consequences of the task they are carrying out.

Aiken et al. (2012) argue that the health care management model developed in Spain is based on containing costs, and this limits professional intervention and indirectly forces the family to become more involved in looking after someone in a situation of dependence. The analysis showed there was a generalized negative view of the system's functioning and structure, with improvement strategies being proposed to avoid the consequences of care for the family and the principal caregiver, an aspect that has been covered in detail in the recent scientific literature (Blanthorn-Hazell, Gracia, Roberts, Boldeanu, & Judge, 2018; Yu, Chen, Hu, & Hu, 2018). Despite the participants' pessimism with regard to the current problematic situation, Kulhara et al. (2012) argue that there are many psychological variables such as coping strategies, religious practices and perceived social support that have a certain amount of influence on the positive experience of caring. They suggest that there is a need to identify and promote factors that contribute to positive caring.

The results of the investigation are clear: Spain is a country characterized by familism or family solidarity which makes the family responsible for the care of its dependent members (Mínguez, 2017). As pointed out by the participants, it also stigmatizes the mental health system, allocating it fewer professionals and care facilities than other health services (Inchauspe, 2012),

thereby giving shape to a public system that is incapable of providing the necessary resources to meet the requirements of people with SMD who need support and care to carry out the basic and instrumental activities of daily life. In line with WHO recommendations (2011), the study participants would like to see the restructuring of a system that is today known for five critical characteristics: 1) its lack of financial and human resources for mental health, 2) its lack of effective coordination among all the institutions and authorities involved (social services, primary health care, specialist health care, employment, housing ...), 3) its lack of quality resources aimed at rehabilitation and social reintegration as alternatives to institutionalization, 4) its lack of integrated care, and 5) its lack of a common healthcare framework for all professional workers in all the regions. A remodeling of the system is necessary to enable the rehabilitation, recovery, empowerment and development of people with SMD and thus lift the burden from family caregivers.

The present study focuses on a critical view of the system from a social work standpoint and other healthcare professionals, drawing attention to the lack of strategic planning in mental health and stressing the need to reorganize the health care resources network in line with the community health care model – oriented toward the person's recovery and their full social inclusion (Davidson, 2016; Kidd, McKenzie, & Virdee, 2014; Lietz, Lacasse, Hayes, & Cheung, 2014) – and to improve infrastructures and bring the provision of certain facilities and human resources up to full strength. The social worker's role in this case about the family should consist basically of assessing their situation, informing them, advising them and involving them in the entire illness process. Following Tew et al. (2012) and Golightley and Goemans (2017), the social workers interviewed maintained that social work as a profession dealing with change should promote improvements in the quality of life and the health levels of people with SMD and their families. For this to happen, the system needs to provide integrated biopsychosocial care to those who need it and their families, understanding the reality of the problem and boosting and strengthening the healthier aspects of the patient so as to satisfactorily guarantee their welfare.

Conclusion

Families in Spain stand in for the lack of public resources allocated to mental health care (residential homes, rehabilitation centers and sheltered housing). They therefore play an indispensable substitute role for the person suffering from SMD because the operative ability of the state in this area is insufficient. Thus, having clients remain with their families has become an end in itself, regardless of whether it is viable or suitable in the real situation, since the family is not given even the minimum resources to carry out the care. The specific consequences of informal care for those responsible for it continues to be a common challenge. The response needs to include (1) the strengthening of

the law of dependence, (2) the creation of real care policies for people with mental illness aimed at improving quality of life for them and their caregivers, and (3) the provision of resources and interventions capable of ensuring the welfare of this collective. The state should give formal support to the family, using mental health care facilities to provide caregivers with psychosocial care and designing protection policies to provide informal caregivers with care and social and economic recognition. Giving effective support to family and caregivers is an institutional responsibility that would enable the public health services involved in mental health care to respond with guarantees.

Acknowledgments

We thank all the professional participants for giving their time and energy to this study.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the Generalitat Valenciana and European Social Fund (ESF) [ACIF/2017/284].

References

- Ahmed, R., Bruce, S., & Jurcik, T. (2018). Towards a socioecological framework to support mental health caregivers: Implications for social work practice and education. *Social Work in Mental Health, 16*(1), 105–122. doi:10.1080/15332985.2017.1336744
- Aiken, L. H., Sermeus, W., Van Den Heede, K., Sloane, D. M., Busse, R., McKee, M., ... Tishelman, C. (2012). Patient safety, satisfaction, and quality of hospital care: Cross sectional surveys of nurses and patients in 12 countries in Europe and the United States. *The BMJ, 344*, e1717. doi:10.1136/bmj.e1717
- Akbari, M., Alavi, M., Irajpour, A., & Maghsoudi, J. (2018). Challenges of family caregivers of patients with mental disorders in Iran: A narrative review. *Iranian Journal of Nursing and Midwifery Research, 23*(5), 329. doi:10.4103/ijnmr.IJNMR_122_17
- Alexander, G., Bebee, C. E., Chen, K. M., Des Vignes, R. M., Dixon, B., Escoffery, R., ... Nelson, M. (2016). Burden of caregivers of adult patients with schizophrenia in a predominantly African ancestry population. *Quality of Life Research, 25*(2), 393–400. doi:10.1007/s11136-015-1077-5
- Aylaz, R., & Yıldız, E. (2018). The care burden and coping levels of chronic psychiatric patients' caregivers. *Perspectives in Psychiatric Care, 54*(2), 230–241. doi:10.1111/ppc.12228
- Blanthorn-Hazell, S., Gracia, A., Roberts, J., Boldeanu, A., & Judge, D. (2018). A survey of caregiver burden in those providing informal care for patients with schizophrenia or bipolar disorder with agitation: Results from a European study. *Annals of General Psychiatry, 17*(1), 8. doi:10.1186/s12991-018-0178-2

- Coffey, A., & Atkinson, P. (2003). Los conceptos y la codificación. In A. Coffey & P. Atkinson (Eds), *Encontrar el sentido a los datos cualitativos* (pp. 31–63). Medellín, Colombia: Universidad Nacional de Antioquia.
- Consejo General del Trabajo Social. (2012). *Código deontológico de Trabajo Social*. Retrieved from https://www.cgtrabajosocial.es/codigo_deontologico
- Davidson, L. (2016). The recovery movement: Implications for mental health care and enabling people to participate fully in life. *Health Affairs*, 35(6), 1091–1097. doi:10.1377/hlthaff.2016.0153
- Denzin, N. K. (1970). *Sociological methods: A source book*. Chicago, USA: Aldine Publishing Company.
- Dockery, L., Jeffery, D., Schauman, O., Williams, P., Farrelly, S., Bonnington, O., ... Clement, S. (2015). Stigma-and non-stigma-related treatment barriers to mental healthcare reported by service users and caregivers. *Psychiatry Research*, 228(3), 612–619. doi:10.1016/j.psychres.2015.05.044
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196(4286), 129–136. doi:10.1126/science.847460
- Forsman, A. K., Wahlbeck, K., Aarø, L. E., Alonso, J., Barry, M. M., Brunn, M., ... Evans-Lacko, S. (2015). Research priorities for public mental health in Europe: Recommendations of the ROAMER project. *The European Journal of Public Health*, 25(2), 249–254. doi:10.1093/eurpub/cku232
- Gater, A., Rofail, D., Tolley, C., Marshall, C., Abetz-Webb, L., Zarit, S. H., & Berardo, C. G. (2014). “Sometimes it’s difficult to have a normal life”: Results from a qualitative study exploring caregiver burden in schizophrenia. *Schizophrenia Research and Treatment*, 2014, 1–13. doi:10.1155/2014/368215
- Golightly, M., & Goemans, R. (2017). *Social work and mental health*. London, United Kingdom: Learning Matters.
- Gomes, T. B., & Dos Santos, J. B. (2016). Dilemmas and setbacks of families in social vulnerability in the context of psychiatric deinstitutionalization. *Physis: Revista De Saúde Coletiva*, 26(1), 271–287. doi:10.1590/S0103-73312016000100015
- Gopal, S., Xu, H., McQuarrie, K., Savitz, A., Nuamah, I., Woodruff, K., & Mathews, M. (2017). Caregiver burden in schizophrenia following paliperidone palmitate long acting injectables treatment: Pooled analysis of two double-blind randomized phase three studies. *NPJ Schizophrenia*, 3(1), 23. doi:10.1038/s41537-017-0025-5
- Guedes, L., Pereira, A., & Chaves, C. (2017). Influence of sociodemographic and clinical characteristics on the quality of life of patients with schizophrenia. *Revista Escola De Enfermagem Da USP*, 51. doi:10.1590/S1980-220X2016031903244
- Guillén, A. M., González, S., & Luque, D. (2016). Austeridad y ajustes sociales en el sur de Europa. La fragmentación del modelo de bienestar mediterráneo. *Revista Española De Sociología*, 25(2), 261–272.
- Hong, M., & Casado, B. L. (2015). Caregiver stress: Does states’ expenditure on home- and community based services matter? *Home Health Care Services Quarterly*, 34(2), 85–100. doi:10.1080/01621424.2015.1029186
- Inchauspe, J. A. (2012). Crise économique, politiques d’austérité et soins en santé mentale en Espagne. *L’information Psychiatrique*, 88(3), 167–175. doi:10.3917/inpsy.8803.0167
- Jagannathan, A., Thirthalli, J., Hamza, A., Nagendra, H. R., & Gangadhar, B. N. (2014). Predictors of family caregiver burden in schizophrenia: Study from an in-patient tertiary care hospital in India. *Asian Journal of Psychiatry*, 8, 94–98. doi:10.1016/j.ajp.2013.12.018
- Jiménez, J. F. (2011). El papel del Observatorio de Salud Mental y los criterios de calidad asistencial de la AEN en la evaluación y planificación asistencial: Recursos de profesionales en CSM y de dispositivos de atención a pacientes con TMG en España. *Revista De La*

- Asociación Española De Neuropsiquiatría*, 31(4), 735–751. doi:10.4321/S0211-57352011000400011
- Kidd, S. A., McKenzie, K. J., & Virdee, G. (2014). Mental health reform at a systems level: Widening the lens on recovery-oriented care. *The Canadian Journal of Psychiatry*, 59(5), 243–249. doi:10.1177/070674371405900503
- Krishnan, V., & Sood, M. (2017). Changing patterns of caregiver burden: A comparison of family burden studies in schizophrenia over four decades from India. *Schizophrenia Bulletin*, 43(Suppl 1), S255. doi:10.1093/schbul/sbx022.117
- Kulhara, P., Kate, N., Grover, S., & Nehra, R. (2012). Positive aspects of caregiving in schizophrenia: A review. *World Journal of Psychiatry*, 2(3), 43. doi:10.5498/wjp.v2.i3.43
- Kumar, C. N., Suresha, K. K., Thirthalli, J., Arunachala, U., & Gangadhar, B. N. (2015). Caregiver burden is associated with disability in schizophrenia: Results of a study from a rural setting of south India. *The International Journal of Social Psychiatry*, 61(2), 157–163. doi:10.1177/0020764014537637
- Kung, W. (2016). Tangible needs and external stressors faced by Chinese American families with a member having schizophrenia. *Social Work Research*, 40(1), 53–63. doi:10.1093/swr/svv047
- León, M. (2014). *The transformation of care in European societies*. Basingstoke, UK: Palgrave Macmillan.
- León, M., & Pavolini, E. (2014). ‘Social investment’ or back to ‘Familism’: The impact of the economic crisis on Family and Care Policies in Italy and Spain. *South European Society and Politics*, 19(3), 353–369. doi:10.1080/13608746.2014.948603
- Lietz, C. A., Lacasse, J. R., Hayes, M. J., & Cheung, J. (2014). The role of services in mental health recovery: A qualitative examination of service experiences among individuals diagnosed with serious mental illness. *Journal of the Society for Social Work and Research*, 5(2), 161–188. doi:10.1086/675850
- Martín, B. H. (2013). El Trabajo social en la intervención psicosocial con personas con trastorno mental severo: Una reflexión sobre el papel de las familias. *Documentos De Trabajo Social: Revista De Trabajo Y Acción Social*, 52, 314–325.
- Martin, C. (2015). Southern welfare states: Configuration of the welfare balance between state and the family. In M. Baumeister & R. Sala (Eds), *Southern Europe?: Italy, Spain, Portugal, and Greece from the 1950s until the present day* (pp. 77–100). Frankfurt, Germany: The University of Chicago Press.
- Mínguez, A. M. (2017). Understanding the impact of economic crisis on inequality, household structure, and family support in Spain from a comparative perspective. *Journal of Poverty*, 21(5), 454–481. doi:10.1080/10875549.2017.1348422
- Mosca, I., Van der Wees, P. J., Mot, E. S., Wammes, J. J., & Jeurissen, P. P. (2017). Sustainability of long-term care: Puzzling tasks ahead for policy-makers. *International Journal of Health Policy and Management*, 6(4), 195–205. doi:10.15171/ijhpm.2016.109
- Naldini, M., Pavolini, E., & Solera, C. (2016). Female employment and elderly care: The role of care policies and culture in 21 European countries. *Work, Employment and Society*, 30(4), 607–630. doi:10.1177/0950017015625602
- Narasipuram, S., & Kasimahanti, S. (2012). Quality of life and perception of burden among caregivers of persons with mental illness. *Journal of Psychological Medicine*, 13(2), 99–103.
- Navarro-Pérez, J. J., & Carbonell, A. (2018). Family burden, social support and community health in caregivers of people with serious mental disorder. *Revista da Escola de Enfermagem da USP*, 52, 1–7. doi:10.1590/S1980-220X2017029403351
- Peña-Longobardo, L. M., Oliva-Moreno, J., García-Armesto, S., & Hernández-Quevedo, C. (2016). The Spanish long-term care system in transition: Ten years since the 2006 dependency act. *Health Policy*, 120(10), 1177–1182. doi:10.1016/j.healthpol.2016.08.012

- Revenson, T. A., Griva, K., Luszczynska, A., Morrison, V., Panagopoulou, E., Vilchinsky, N., & Hagedoorn, M. (2016). Gender and caregiving: The costs of caregiving for women. In T. A. Revenson, K. Griva, A. Luszczynska, V. Morrison, E. Panagopoulou, N. Vilchinsky, M., & Hagedoorn (Eds.), *Caregiving in the illness context*. London, United Kingdom: Palgrave Pivot.
- Saldaña, J. (2015). *The coding manual for qualitative researchers*. Los Angeles, USA: Sage Publications.
- Saraceno, C. (2016). Varieties of familism: Comparing four southern European and East Asian welfare regimes. *Journal of European Social Policy*, 26(4), 314–326. doi:10.1177/0958928716657275
- Shea, S. C. (2016). *Psychiatric interviewing: The art of understanding: A practical guide for psychiatrists, psychologists, counselors, social workers, nurses, and other mental health professionals* (3rd edition). New York, USA: Elsevier Health Sciences.
- Soto, F. L., Espinosa, C., Vega, J., & Vega, S. (2012). Sobrecargas objetivas y nivel de apoyo familiar a pacientes adultos con esquizofrenia. *Salud Uninorte*, 28(2), 218–226.
- Stanley, S., Balakrishnan, S., & Ilangovan, S. (2017). Psychological distress, perceived burden and quality of life in caregivers of persons with schizophrenia. *Journal of Mental Health*, 26(2), 134–141. doi:10.1080/09638237.2016.1276537
- Stein, G. L., Gonzalez, L. M., Cupito, A. M., Kiang, L., & Supple, A. J. (2015). The protective role of familism in the lives of Latino adolescents. *Journal of Family Issues*, 36(10), 1255–1273. doi:10.1080/13608746.2014.948603
- Tew, J., Ramon, S., Slade, M., Bird, V., Melton, J., & Le Boutillier, C. (2012). Social factors and recovery from mental health difficulties: A review of the evidence. *The British Journal of Social Work*, 42(3), 443–460. doi:10.1093/bjsw/bcr076
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. doi:10.1093/intqhc/mzm042
- Vaquiro, S., & Stieповich, J. (2010). Cuidado informal, un reto asumido por la mujer. *Revista Ciencia Y Enfermería*, XVI, 9–16.
- World Health Organization. (2005). Mental Health Declaration for Europe. Facing the Challenges, Building Solutions. Retrieved from http://www.euro.who.int/_data/assets/pdf_file/0008/88595/E85445.pdf
- World Health Organization. (2011). *Mental Health Atlas*. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/44697/9799241564359_eng.pdf;jsessionid=1F41F01C16FC146F7707D65341779228?sequence=1
- World Health Organization. (2017). *Mental health ATLAS 2017*. Retrieved from <http://apps.who.int/iris/bitstream/handle/10665/272735/9789241514019-eng.pdf?ua=1>
- Yu, W., Chen, J., Hu, J., & Hu, J. (2018). Relationship between mental health and burden among primary caregivers of outpatients with schizophrenia. *Family Process*, 1, 1–14. doi:10.1111/famp.12340