TESIS DOCTORAL

Brechas de las políticas públicas y la intervención profesional

FAMILISMO Y CUIDADOS EN SALUD MENTAL

Autora:

Ángela Carbonell Marqués

Directores:

Dr. José Javier Navarro Pérez
Dra. María Vicenta Mestre Escrivá

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Raúl Gómez Sanz

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Resumen

La atención en salud mental ha sufrido grandes cambios epistemológicos y prácticos, representando un largo y complejo proceso histórico y cultural. En la actualidad, el aumento de la prevalencia de los trastornos mentales y la limitada disponibilidad de recursos hace que la atención a la salud mental recaiga sobre la familia. Esta se ha constituido como principal proveedor de atención y apoyo continuo, asumiendo así la carga derivada del cuidado, especialmente la persona que ejerce el rol de cuidadora principal.

A través del compendio de publicaciones científicas, la finalidad de esta tesis doctoral es conocer y explicar de manera crítica e integral los desafíos y barreras que envuelven el cuidado familiar de personas con trastorno mental, profundizando en los factores individuales de las cuidadoras y personas cuidadas y las vulnerabilidades asociadas a los sistemas de atención a la salud mental. Los objetivos específicos que persigue esta tesis son 1) explorar los factores asociados a la sobrecarga de las cuidadoras familiares de personas con trastorno mental, 2) conocer la percepción de los profesionales de la salud mental sobre el cuidado familiar y la gestión de las políticas públicas en este ámbito, y 3) analizar los desafíos y barreras de los sistemas de atención a la salud mental y su impacto en la familia. Para alcanzar estos objetivos, esta tesis utiliza una perspectiva de métodos mixtos que involucra cuatro artículos científicos y tres procesos de investigación, utilizando metodologías cualitativas y cuantitativas que permiten obtener una visión general, completa y crítica del objeto de estudio.

Los datos arrojados por los diferentes estudios permiten afirmar la existencia de una serie de barreras estructurales, culturales, económicas y de tratamiento que suponen brechas de las políticas públicas y la intervención profesional en salud mental. Ante estas deficiencias del sistema y la ausencia de apoyo formal, la familia se ha consolidado como la principal proveedora de cuidados, asumiendo el cuidado continuo y los costos psicosociales, económicos y laborales que se generan para garantizar su propio bienestar.

Palabras clave: salud mental; familismo; cuidado familiar; recuperación; métodos mixtos.

Abstract

Mental healthcare has undergone far-reaching epistemological and practical changes, representing a long and complex historical and cultural process. Today the increased prevalence of mental illness and the limited availability of resources means that mental healthcare falls to the family. Families have thus become the main providers of continuous care and support, taking on the burden of responsibility to look after the person with mental illness, and this is especially true of whoever takes on the role of main caregiver.

In the form of a compendium of scientific publications, this doctoral thesis seeks to ascertain and thoroughly explain from a critical point of view the challenges and barriers involved in the family care of people with mental illness. It explores in depth the individual factors relating to those giving and receiving care and the shortcomings associated with mental healthcare systems. The specific aims are 1) to explore the factors associated with overload in family caregivers of people with mental illness, 2) to find out how mental health professionals perceive family care and the way public policies in this area are managed, and 3) to analyse the challenges and barriers of mental healthcare systems and their impact on the family. In order to achieve these aims, the thesis follows a mixed methods approach that includes four scientific articles and three research processes. It uses qualitative and quantitative methodologies to obtain a comprehensive and critical overview of the object of study.

The data obtained in the different studies makes it clear that there exists a series of structural, cultural, economic and treatment barriers that cause shortcomings in public policies and professional intervention in the area of mental health. Given these deficiencies in the system and the absence of formal support, the family has become the main provider, assuming responsibility for continuous care along with the psychosocial, economic, and labour costs that this entails in order to guarantee its own well-being.

Keywords: mental health, familism, family care, recovery, mixed methods.

Resum

L'atenció en salut mental ha patit grans canvis epistemològics i pràctics, representant un llarg i complex procés històric i cultural. En l'actualitat, l'augment de la prevalença dels trastorns mentals i la limitada disponibilitat de recursos fa que l'atenció a la salut mental recaiga sobre la família. Aquesta s'ha constituït com a principal proveïdor d'atenció i suport continu, assumint així la càrrega derivada de la cura, especialment la persona que exerceix el rol de cuidadora principal.

A través del compendi de publicacions científiques, la finalitat d'aquesta tesi doctoral és conéixer i explicar de manera crítica i integral els desafiaments i barreres que emboliquen la cura familiar de persones amb trastorn mental, aprofundint en els factors individuals de les cuidadores i persones cuidades i les vulnerabilitats associades als sistemes d'atenció a la salut mental. Els objectius específics que persegueix aquesta tesi són 1) explorar els factors associats a la sobrecàrrega de les cuidadores familiars de persones amb trastorn mental, 2) conéixer la percepció dels professionals de la salut mental sobre la cura familiar i la gestió de les polítiques públiques en aquest àmbit, i 3) analitzar els desafiaments i barreres dels sistemes d'atenció a la salut mental i el seu impacte en la família. Per a aconseguir aquests objectius, aquesta tesi utilitza una perspectiva de mètodes mixtos que involucra tres processos d'investigació, utilitzant metodologies qualitatives i quantitatives que permeten obtindre una visió general, completa i crítica de l'objecte d'estudi.

Les dades llançades pels diferents estudis permeten afirmar l'existència d'una sèrie de barreres estructurals, culturals, econòmiques i de tractament que suposen bretxes de les polítiques públiques i la intervenció professional en salut mental. Davant aquestes deficiències del sistema i l'absència de suport formal, la família s'ha consolidat com la principal proveïdora de cures, assumint la cura contínua i els costos psicosocials, econòmics i laborals que es generen per a garantir el seu propi benestar.

Paraules clau: salut mental; familisme; cura familiar; recuperació; mètodes mixtos.

A Isabel,

por ayudarme a encontrar mi propósito en el caos.

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Índice

Presentación

La salud mental se considera un elemento esencial e inseparable de la salud y está directamente relacionada con el bienestar individual, familiar y comunitario. La Organización Mundial de la Salud (en adelante, WHO) sostiene que, en la actualidad, los trastornos mentales son considerados un problema de salud pública de especial relevancia, debido a las repercusiones negativas que tienen sobre la salud y calidad de vida de las personas y sus familiares, y sobre el funcionamiento del propio sistema de atención. Las personas con trastorno mental[1] a menudo requieren de asistencia a largo plazo debido a las limitaciones físicas y cognitivas derivadas de la enfermedad. El aumento de la prevalencia de estos trastornos, así como la limitada disponibilidad de recursos, hace que este cuidado a menudo recaiga sobre la familia. Esta se ha constituido como principal proveedor de atención y apoyo continuo, asumiendo así la carga derivada del cuidado, especialmente la persona que ejerce el rol de cuidadora principal que, casi en exclusiva, suele ser una mujer.

La presente tesis doctoral lleva por título “Brechas de la intervención profesional y las políticas públicas: familismo y cuidados en salud mental” y es el resultado del interés por conocer y explicar de manera crítica e integral los desafíos y barreras que envuelven el cuidado familiar de personas con trastorno mental, profundizando en los factores individuales de las cuidadoras y personas cuidadas y las vulnerabilidades asociadas a los sistemas de atención a la salud mental.

Para ello, los objetivos que persigue esta tesis doctoral son 1) explorar los factores asociados a la sobrecarga de las cuidadoras familiares de personas con trastorno mental, 2) conocer la percepción de los profesionales de la salud mental sobre el cuidado familiar y la gestión de las políticas públicas en este ámbito, y 3) analizar los desafíos y barreras de los sistemas de atención a la salud mental y su impacto en la familia. Para alcanzar estos objetivos, esta tesis utiliza una perspectiva de métodos mixtos que involucra tres

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[1] En la presente investigación se hace referencia a las “personas con trastorno mental”, definidas para este estudio como personas adultas que, diagnosticadas de trastornos mentales que suponen afectaciones específicas graves, cuentan con limitaciones en su autonomía personal y requieren del cuidado y apoyo de otra persona para el desarrollo las actividades del día a día.

procesos de investigación y metodologías cualitativas y cuantitativas que permiten obtener una visión general, completa y crítica del objeto de estudio.

La modalidad escogida para esta tesis doctoral es la presentación por compendio de publicaciones. Esto ha permitido desarrollar este trabajo al mismo tiempo que se publican los resultados, ampliando así mi currículum académico y consolidando mi perfil como investigadora. Del mismo modo, los artículos que conforman esta tesis doctoral han sido revisados por investigadores e investigadoras expertos/as en la temática que, mediante sugerencias y comentarios, han enriquecido y avalado la calidad de esta investigación.

La realización de esta tesis me ha permitido no sólo un aprendizaje de los procesos y prácticas de publicación, sino también un aprendizaje en metodologías de investigación de alta calidad muy reclamadas por la literatura científica, como son las revisiones sistemáticas, que hasta hace nada eran desconocidas para mí. La formación y supervisión mi director y codirectora de tesis -los cuales han contribuido en el diseño, interpretación de resultados y redacción de estos artículos- han sido vitales para asumir los complejos caminos de publicación y desarrollo de este estudio.

La normativa de la Universitat de València y del Programa de Doctorado en Ciencias Sociales establece que para que el compendio sea evaluado como tesis doctoral debe incluir, además de una copia de los artículos publicados, un resumen global de la temática, de los principales resultados y de las conclusiones, que justifique la aportación original del autor o autora. No obstante, debido al arduo trabajo que ha supuesto desarrollar una tesis doctoral por compendio de publicaciones, se ha querido destacar la condición de esta modalidad durante la redacción de estas páginas. Por ello, y con el objetivo de ofrecer una mayor coherencia a esta investigación, la presente tesis doctoral se divide en siete capítulos:

- La primera sección comprende el marco teórico de la investigación, el cual incluye de manera coherente las conceptualizaciones teóricas y estudios previos sobre el tema. Este capítulo profundiza en la evolución de la atención a la salud mental a nivel global y, más concretamente, desde el contexto español, y profundiza en la situación del cuidado familiar y los factores que contibuyen a la sobrecarga de las cuidadoras. Además, introduce un apartado sobre la inclusión de la salud mental como objetivo de desarrollo internacional.

- En el capítulo dos, se definen el objeto y objetivos de esta tesis doctoral, y las prioridades de investigación descritas por la literatura que sirven como hoja de ruta para el desarrollo de este estudio. Asimismo, se incluyen los paradigmas y modelos en los que se apoya esta investigación.

- El tercer capítulo profundiza en los desafíos y fortalezas que supone la publicación científica y el desarrollo de una tesis por compendio de publicaciones en el marco de las Ciencias Sociales, y describe la metodología empleada para cada fase de investigación siguiendo un modelo de métodos mixtos. Asimismo, se incide en las decisiones relativas a la autoría y se realiza un análisis bibliométrico y evaluación de la calidad de las revistas científicas seleccionadas para la publicación de resultados.

- En el cuarto capítulo, se presentan los cuatro estudios empíricos publicados, incluyendo la introducción, metodología, resultados, discusión y referencias de cada uno de ellos.

- El quinto capítulo de esta Tesis Doctoral incluye las conclusiones que permiten resumir los hallazgos más significativos del estudio. Debido a que esta es una tesis con mención internacional, esta sección se ha redactado también en inglés, como lengua habitual para la comunicación científica en este campo de conocimiento.

- Finalmente, el sexto y séptimo capítulo comprenden, respectivamente, las referencias bibliográficas consultadas para desarrollar el cuerpo teórico en el que se apoya esta investigación y los artículos originales publicados y otros materiales complementarios.

La investigación que se presenta a continuación aporta nuevos resultados y conclusiones al ámbito del cuidado familiar en salud mental desde una visión holística de la vulnerabilidad, y de esta manera potencia la necesidad de hacer frente a los desafíos y barreras que envuelven los trastornos mentales y el impacto en la familia.

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CAPÍTULO 1. MARCO TEÓRICO DE LA INVESTIGACIÓN

1.1. La Evolución de la Atención: De la Psiquiatría a la Salud Mental

Durante los últimos años, el uso del concepto de “enfermedad mental” se ha tratado de abolir gradualmente para incorporar términos menos estigmatizantes como “salud mental” o “trastorno mental” (Chekroud et al., 2017; Hallam, 2018), aun así, su uso sigue siendo común en la literatura científica. La salud mental es un componente integral y esencial de la salud. La Constitución de la Organización Mundial de la Salud (WHO, 2006) define la salud como un estado de completo bienestar físico, mental y social.

Las definiciones de salud mental varían según la disciplina y la cultura. La Organización Mundial de la Salud (WHO, 2003) destaca la importancia de la dimensión positiva de la salud mental y matiza que es algo más que la mera ausencia de trastornos mentales o discapacidades. La salud mental y el bienestar de la población tienen un impacto significativo en los países y en su capital humano, social, mental y económico. Este concepto incluye el bienestar subjetivo, la autoeficacia percibida, la autonomía, la competencia, la dependencia intergeneracional y el reconocimiento de la capacidad de desarrollar el potencial intelectual y emocional de cada persona. La salud mental también se ha definido como un estado de bienestar en el que las personas reconocen sus capacidades, son capaces de hacer frente al estrés cotidiano, trabajan de manera productiva y fructífera, y contribuyen a sus comunidades (WHO, 2018).

Spitzer et al. (2018) definen el trastorno mental como un trastorno médico cuyas manifestaciones son principalmente signos o síntomas de naturaleza psicológica o conductual, generalmente caracterizados por una combinación de pensamientos, emociones, relaciones con los demás, o comportamientos anómalos (James et al., 2018). Según Garcés et al. (2002), la cronicidad de estos trastornos conlleva un alto grado de discapacidad que afecta a todas las esferas de la vida -física, psíquica y social- y se consideran predictores de riesgo de dependencia, pues conllevan una gran pérdida de autonomía y requieren de atención y asistencia constante para llevar a cabo las actividades básicas e instrumentales de la vida diaria.

La atención en salud mental ha sufrido grandes cambios epistemológicos y prácticos, representando un largo y complejo proceso histórico y cultural. Hasta mediados del siglo XX la psiquiatría únicamente ofrecía encierros por periodos indefinidos de tiempo y prácticas drásticas para controlar las enfermedades mentales graves, como la terapia electroconvulsiva o las lobotomías (Engstrom, 2012; Goffman, 1968). La introducción de la psicofarmacología, la ausencia de intervenciones terapéuticas y el progresivo hacinamiento en los manicomios provocó el uso de medidas represivas físicas y/o químicas para imponer el orden interno (Drew et al., 2011). Los establecimientos psiquiátricos se convirtieron, a nivel mundial, en un sinónimo de violación de derechos humanos y de violencia institucional marcados por el abandono, la indignidad, el trato inhumano y el castigo de las personas con trastorno mental (Gostin, 2008).

Por ello, Naciones Unidas (United Nations, 1991) y la WHO (2001) vienen cuestionando desde hace muchos años el papel de las instituciones psiquiátricas y los procesos asistenciales frente a la enfermedad mental. El modelo biomédico predominante y la psiquiatría tradicional consideran que los trastornos mentales son enfermedades cerebrales con base biológica y postulan que la farmacología es el único tratamiento adecuado para atacar estas supuestas anomalías biológicas. Este modelo fue duramente criticado por Engel (1977), quien sostenía que los trastornos mentales son enfermedades que van más allá de lo biológico y deben atender dimensiones sociales, psicológicas y conductuales. El análisis crítico de Deacon (2013) sobre la validez del modelo biomédico hegemónico en Estados Unidos, concluyó que a pesar de los avances que ha alcanzado este paradigma –desarrollo de la industria farmacéutica y la psiquiatría–, se caracteriza por una amplia falta de innovación clínica y malos resultados de salud mental.

En los años sesenta en Estados Unidos empezó un movimiento de reformas de salud mental. La aparición de nuevos modelos comunitarios de atención a personas con trastorno mental, basados en criterios de calidad de vida y atención digna, y el desarrollo incipiente de la psicofarmacología, supusieron el inicio del movimiento de desinstitucionalización psiquiátrica (Ahmed et al., 2018), considerando el cierre de los hospitales psiquiátricos y la inserción de las personas con trastorno mental en la comunidad (Fauble, 2016; Zegwaard et al., 2015). La ley estadounidense de salud mental comunitaria (Community Mental Health Act, 1963) asentó las bases para el movimiento moderno de salud mental comunitaria marcando el inicio de un cambio muy ambicioso en objetivos, pero que fue extendiéndose rápidamente por toda Europa (Jordan, 2020).

La filosofía de la reforma psiquiátrica procuraba integrar la salud mental con los servicios de salud y los servicios sociales y comunitarios (Becker & Vázquez-Barquero, 2001), y garantizaba el diseño e incorporación de nuevos servicios comunitarios terapéuticos y la creación de recursos y programas más eficaces, más solidarios y humanitarios que subyacían del movimiento de defensa de los derechos humanos (Juan-Porcar et al., 2015). La política de desinstitucionalización fue, por tanto, una política social que exigía un cambio en la atención y cuidado de las personas con trastornos mentales (Chow & Priebe, 2013). Desde su culminación, los recursos psiquiátricos, especialmente en países europeos, pasaron de estar basados en hospitales psiquiátricos a intervenciones comunitarias integradas generalmente dentro de los sistemas de salud, reduciendo el límite físico y el aislamiento que caracterizaban los tradicionales manicomios (Quirk et al., 2006; Johnson et al., 2009).

La reforma psiquiátrica también trajo consigo un cambio de paradigma en la teoría y la práctica profesional (Jacob, 2015). En las décadas posteriores, el impulso del movimiento antipsiquiatría abogó por diferentes modelos y enfoques de atención centrados en la participación de las personas usuarias y en la provisión de servicios (Cooper, 1967). El asesoramiento centrado en el cliente de Roger (1986) y las terapias cognitivo-conductuales, entre muchas otras, supusieron un avance exitoso en la atención a la salud mental. El modelo de recuperación surgió entonces como antagonista al modelo biomédico tradicional predominante en salud mental (Thornton & Lucas, 2011). Randal et al. (2009) lo definen como un enfoque integrador del desarrollo estrés-vulnerabilidad-fortalezas para la salud mental que argumenta que la comprensión total de la persona debe incluir el reconocimiento y potencialización de sus capacidades, metas y confianza junto con los síntomas, traumas, disfunciones y discapacidades derivados de la enfermedad. Como señalan Newman et al. (2015), este modelo defiende la prominencia e importancia de la atención centrada en la persona, garantizando que se respeten sus necesidades y preferencias y que los usuarios y usuarias de los servicios puedan tomar decisiones informadas sobre su atención y contribuir a ellas. El modelo de recuperación no se centra en la reducción o resolución completa de los síntomas de la enfermedad mental, sino que hace hincapié en la autodeterminación, la resiliencia, y el control de la enfermedad y de la propia vida (Ford, 2016; McCauley et al., 2015).

A partir de los años 80, los procesos de reforma psiquiátrica y el cambio de paradigma en salud mental se aceleraron en muchos países, incorporando acciones de desinstitucionalización, desarrollo de programas y servicios comunitarios alternativos, integración con los servicios de salud y con los servicios sociales y comunitarios. En 2012, la Asamblea Mundial de la Salud aprobó el Plan de Acción Integral sobre Salud Mental 2013–2020 (WHO, 2012), el cual instaba a todos los Estados Miembros al desarrollo de servicios, políticas, leyes, planes, estrategias y programas que abarcaran la promoción, prevención, tratamiento, rehabilitación, atención y recuperación de la salud mental adaptados a las necesidades existentes en cada territorio. No obstante, numerosos estudios han concluido en que las reformas no adquirieron la fuerza suficiente para alcanzar sus objetivos (Angelic, 2018; Chondros & Stylianidis, 2016).

En este sentido, la salud mental no adquirió el protagonismo o importancia esperado, lo cual pone en evidencia el actual abandono y apatía general existente hacia la salud mental y la priorización de la salud física para el desarrollo y la implementación de políticas públicas (Mills, 2018; Salvador-Carulla et al., 2002). Desde el inicio de la reforma, el cierre de los hospitales psiquiátricos provocó el alta médica de miles de personas con trastorno mental incapaces de vivir de manera independiente. En países como Estados Unidos, la insuficiencia de recursos comunitarios para atender a la población psiquiátrica hizo que las familias de muchos usuarios y usuarias asumieran el cuidado, o que estas acabaran en situación de sinhogarismo o presas en centros penitenciarios (Foerschner et al., 2010; Leff, 2001). Según Wurtzburg y Thomson (2014), esto provocó, en muchos casos, la sobremedicalización para evitar la confrontación de los trastornos mentales.

1.1.1. Salud Mental: Una Historia de Estigma y Exclusión Social

Los terminos de exclusión e inclusión social se han vuelto cada vez más prominentes dentro de la literatura científica y la política. O’Donnell et al. (2018) conceptualizan la exclusión como el estado de desventaja al que se enfrentan ciertos grupos sociales que son alejados de la sociedad, negándoles, en múltiples ocasiones, el acceso a recursos y oportunidades que están disponibles para el resto. En casi todas las sociedades, determinados colectivos están sometidos a actitudes y comportamientos excluyentes debido a la pertenencia a una etnia, discapacidad, género o orientación sexual. Las personas con trastorno mental han sido identificados como colectivo especialmente vulnerable a la exclusión social, una carga añadida a los efectos negativos de la propia enfermedad (Davey & Gordon, 2017).

Mucho más que cualquier otra enfermedad, los trastornos mentales han estado y están sujetos a juicios negativos y estigmatización. El término estigma deriva de la palabra latín "stigma, -atis", que significa marca hecha con marca candente, e incluye actitudes negativas, creencias, y comportamientos influenciados por la cultura, los valores y las normas sociales (Arboleda-Flórez & Stuart, 2012). La literatura científica avala la existencia de diversos estigmas relacionados con las enfermedades mentales. El estigma público hace referencia a las actitudes o creencias negativas que tiene la sociedad sobre las enfermedades mentales (Pescosolido, 2013). En contraste, el autoestigma o estigma internalizado se refiere al estigma uno tiene sobre sí mismo, y que implica una reducción de la autoestima como resultado de internalizar el estigma público (Boyd et al., 2014; Clement et al., 2015). Rössler (2016) y Goffman (1963) señalan que el estigma hacia la enfermedad mental es universal, y no existe ningún país en el mundo donde una persona con trastorno mental tenga el mismo valor social que otra sin esta condición. Los resultados de Krishnan (2015) mostraron diferencias en el grado de estigmatización según el tipo de trastorno, aunque generalmente prevalece la asociación de los trastornos mentales con la delincuencia, la agresividad, el consumo de drogas o la incapacidad de la persona para hacerse cargo de su propia vida.

La estigmatización viene derivada por el desconocimiento y la desinformación existente sobre las causas de la enfermedad mental (Loubat et al., 2017). Comúnmente se ha asociado a la locura con la hechicería, el encantamiento, o las repercusiones de malas acciones o pensamientos (Labinjo et al., 2020). Durante milenios, la sociedad ha encarcelado, torturado y/o asesinado a las personas con trastorno mental. Hasta hace dos siglos, se consideraba las personas con trastorno mental estaban poseídas o sometidas a castigo divino y eran encarceladas de manera forzosa, encadenadas y/o ejecutadas. La aparición de teorías médicas y explicaciones biológicas produjeron una reducción y, en algunos casos, eliminación de estas prácticas (Lyon & Mortimer-Jones, 2020; Joseph, 2016). No obstante, el papel de las explicaciones sobrenaturales, religiosas o mágicas de los trastornos mentales todavía prevalece en muchos países no occidentales. La revisión realizada por Peteet (2019) sostiene que el pensamiento fundamentalista, la atribución errónea de la psicopatología o las creencias y prácticas curativas tradicionales, en la actualidad, todavía suponen un obstáculo para el tratamiento y la atención de la salud mental.

La literatura sostiene que estos estereotipos conducen al rechazo, la discriminación, la marginalidad, la pobreza, y tiene un impacto significativo en la vida de las personas con trastorno mental. La revisión realizada por Arboleda-Flórez (2016) sostiene que, en la actualidad, el estigma continua creando desigualdades económicas, sociales y políticas, que afectan negativamente al empleo, el desarrollo académico y las relaciones afectivas y emocionales. Asimismo, el estigma se considera una barrera de acceso a servicios de salud mental, pues coarta la búsqueda de atención y la participación y continuidad de tratamiento, privando a las personas con trastorno mental de la posibilidad de disfrutar de una atención integral e integrada (Campo-Arias et al., 2014). Corrigan et al. (2014) señalan dos conjuntos de barreras relacionadas con el estigma y la búsqueda de atención y participación en los servicios. Por un lado, las barreras personales que generan actitudes y comportamientos que afectan las decisiones de salud, tales como el rechazo o abandono del tratamiento, el desconocimiento de la enfermedad, la ausencia de redes de apoyo que promuevan la búsqueda de atención, entre otras; y por otro, las barreras del sistema que incluyen la cobertura de servicios, las condiciones financieras, o las limitaciones de la fuerza laboral que están influenciadas por el estigma. En esta línea, el estudio Kudva et al. (2020) realizado en ocho países asiáticos señala que el estigma supone un desafío para el desarrollo de legislación específica, la adecuada intervención profesional y la provisión de servicios de atención a la salud mental.

A pesar de estas barreras, los movimientos de lucha por los derechos humanos orientados hacia la recuperación marcaron un hito en la lucha contra el estigma y la exclusión social de la enfermedad mental. Como señala la WHO (2019), en la mayoría de países, la reforma psiquiátrica trajo consigo una disminución de las asimetrías medico-paciente y la integración de la salud mental en los sistemas generales de salud, reconociendo a las personas con trastorno mental como sujetos de derechos y de transformación social. De este modo, diferentes investigaciones (Blake & Hatzenbuehler, 2019; Crowther et al., 2019; Wei et al., 2015) defienden que la promoción de acciones de sensibilización, información y educación de diferentes sectores de la población, el decreto de medidas legales de protección a personas con discapacidad, o la creación de sistemas de apoyo y tratamiento asertivo y comunitario, han provocado, en los últimos años, una evolución de las actitudes sociales hacia la enfermedad mental. Esto ha promovido la identificación temprana de los trastornos mentales, la mejora de los comportamientos de búsqueda de ayuda y la creación de redes informales de apoyo. No obstante, los resultados de Coates et al. (2019) reivindican la necesidad de promulgar acciones y estrategias internacionales de concienciación comunitaria para reducir el estigma y mejorar la alfabetización en salud mental, tratando de garantizar el acceso a la atención y la plena inclusión de las personas con trastorno mental en la sociedad.

1.1.2. La Reforma Psiquiátrica en España

Tradicionalmente, la atención a la salud mental en España dependía de las diputaciones provinciales y no estaba integrada como prestación en el sistema de la Seguridad Social (Morales & Rodríguez, 2018). La crisis de la psiquiatría española comenzó a hacerse visible a partir de los años 60, tras una oleada denuncias de violaciones de derechos humanos en diferentes instituciones psiquiátricas y la consecuente creación de la Coordinadora Psiquiátrica en 1972 y la Comisión de Planificación y Organización de la Asistencia Psiquiátrica del Ministerio de Sanidad y Seguridad Social en 1977. La victoria del Partido Socialista en 1982 inició un proceso de reformas sanitarias y en 1983 se creó la Comisión Ministerial para la Reforma Psiquiátrica, la cual marcó un antes y un después en los servicios de salud mental españoles. Como señala Torres-González (2012), el informe publicado por dicha Comisión en 1985 establecía entre sus principios básicos la necesidad de integrar la salud mental dentro del sistema sanitario español y constituir una estructura de apoyo a la Atención Primaria, la incorporación de los factores biopsicosociales de la enfermedad a la intervención profesional, y la priorización de la intervención en el medio comunitario evitando la hospitalización.

Finalmente, la Reforma Psiquiátrica en España se materializó a través de la promulgación de la Ley 14/1986, de 25 de abril, General de Sanidad, la cual recogió los planteamientos fundamentales del informe en el artículo 20:

1. La atención a los problemas de salud mental de la población se realizará en el ámbito comunitario, potenciando los recursos asistenciales a nivel ambulatorio y los sistemas de hospitalización parcial y atención a domicilio, que reduzcan al máximo posible la necesidad de hospitalización. Se

considerarán de modo especial aquellos problemas referentes a la psiquiatría infantil y psicogeriatría.

2. La hospitalización de los pacientes por procesos que así lo requieran se realizará en las unidades psiquiátricas de los hospitales generales.
3. Se desarrollarán los servicios de rehabilitación y reinserción social necesarios para una adecuada atención integral de los problemas del enfermo mental, buscando la necesaria coordinación con los servicios sociales.
4. Los servicios de salud mental y de atención psiquiátrica del sistema sanitario general cubrirán, asimismo, en coordinación con los servicios sociales, los aspectos de prevención primaria y la atención a los problemas psicosociales que acompañan a la pérdida de salud en general.

A partir de ese momento, la construcción del sistema de salud mental quedó en manos de las comunidades autónomas. En las décadas posteriores, se crearon estructuras para la planificación y organización del sistema, así como nuevos recursos y programas de atención a la salud mental integrados en la comunidad, tales como las unidades de hospitalización parcial, atención ambulatoria y domiciliaria, centros de rehabilitación, pisos supervisados, entre otros. La formación de médicos residentes en psiquiatría (Programa MIR) incluyó las especialidades de psicología clínica y enfermería en salud mental con rotaciones obligadas en todas las unidades de atención. Del mismo modo, se modificaron las normativas legales que discriminaban a las personas con trastorno mental, incluidas el Código Civil, el Código Penal y la reforma sanitaria penitenciaria, posibilitando así nuevas modalidades asistenciales y salvaguardando los derechos de este colectivo (Ebsworth & Foster, 2017; Desviat, 2011). Sin duda, la atención psiquiátrica en España mejoró, modificando el modelo asistencial y creando recursos enfocados hacia la rehabilitación y recuperación de la salud mental. No obstante, el compromiso con el cambio se vio limitado por el compromiso de los y las profesionales, las prioridades sanitarias y la voluntad política de cada comunidad autónoma, donde la salud mental fue perdiendo paulatinamente el protagonismo adquirido con la reforma (Juliá-Sanchis et al. 2020).

En 2007 se publica la primera Estrategia en Salud Mental del Sistema Nacional de Salud (SNS), fruto del consenso entre las instituciones públicas sanitarias nacionales y regionales, las sociedades científicas y las asociaciones de personas usuarias, con el objetivo de mejorar el sistema de salud mental en base a criterios de igualdad y excelencia clínica, atendiendo a factores biológicos, psicológicos y sociales desde equipos profesionales multidisciplinares, y a través de la promoción de la salud mental y el tratamiento y prevención de los trastornos mentales. Como señala Aguilera (2020), la estrategia fue renovada para 2009-2013 pero, en la actualidad, lleva más de seis años en desuso, al ser rechazada su última actualización en el Consejo Interterritorial del SNS de 2016.

A pesar de que la salud mental continúa siendo un desafío pendiente en España, las comunidades autónomas (Comunidad de Madrid, 2018; Generalitat Valenciana, 2016; Junta de Andalucía, 2016) han ido desarrollando y actualizando sus propias estrategias y programas dirigidos a mejorar la salud mental de la población española, en base al Plan de Acción Integral sobre Salud Mental 2013–2020 (WHO, 2012). Estos planes, al igual que la última estrategia nacional propuesta, incluyen objetivos y actuaciones en torno a la prevención del suicidio, la salud mental infantoadolescente, la atención a trastornos específicos (patología dual, psicosis temprana o trastornos de la conducta alimentaria), la participación de las personas usuarias y familiares en todo el proceso de recuperación, y la atención a colectivos de riesgo. Todo ello, enfocado desde una perspectiva biopsicosocial de la enfermedad (Salvador-Carulla et al., 2020).

1.1.3. El Trabajo Social en Salud Mental

Los y las profesionales de la salud mental se han ido adaptando a los numerosos cambios en la atención y prestación de servicios de este colectivo. Si bien la salud mental debe ser abordada desde una perspectiva integral, el Trabajo Social se ha consolidado como la disciplina de atención de los factores sociales que inciden, condicionan y determinan, en ocasiones, la propia evolución de la enfermedad (Miranda, 201).

A principios del siglo XX, el Trabajo Social trató de fortalecerse como profesión, alejándose de sus raíces filantrópicas y del trabajo caritativo, no obstante, carecía de su propio cuerpo de conocimientos (Henning, 2018). En ese momento, en Estados Unidos, ante la masificación de los entornos manicomiales, profesionales del Trabajo Social se incorporaron a los hospitales psiquiátricos con el objetivo de abordar la cronicidad de los trastornos mentales desde la intervención social (Silverman, 1985). A partir de entonces, psiquiatras de todo el mundo fueron reconociendo gradualmente el Trabajo Social como profesión esencial dentro del equipo de salud mental (Garcés, 2010). Estos avances, como señala Timms (1964), condujeron a la creación del primer curso de capacitación en trabajo social psiquiátrico que se ofreció en Smith College en 1918, con fuertes influencias del psicoanálisis, la psiquiatría y la psicología, aunque desde una vertiente meramente asistencialista.

A la vez que el Trabajo Social tomaba protagonismo en la atención a la salud mental en todo el mundo, la disciplina se encontraba en una intensa búsqueda de autodefinición, teorización y reconocimiento profesional. A finales de los años 60 surgió el movimiento de reconceptualización impulsado en América Latina (López, 2013) que propuso modificar el objeto del Trabajo Social, alejándose del asistencialismo y adoptando una posición crítica hacia las concepciones tradicionales asociadas al origen de las desigualdades y la superación de las dificultades sociales. El Trabajo Social comenzó a centrar su intervención profesional en la persona y en cómo esta vivencia sus problemas, pasando de considerarla como un mero objeto de intervención a un sujeto de transformación de la realidad (Servio, 2014). Así, el Trabajo Social, se configuró como sujeto político, agente de cambio internacional y eje de la transformación social de las personas y sociedades (Bautista & Castillo, 2020). Según Alayón y Molina (2004), esta orientación incidió en la creación de metodologías comunitarias encaminadas a la defensa, promoción y protección de los derechos humanos, y al amparo y aumento de la calidad de vida de aquellos colectivos que se encontraban en riesgo de exclusión, donde se incluían las personas con trastorno mental.

En España, el desarrollo del Trabajo Social psiquiátrico se hizo más tangible en 1953 cuando se creó la tercera Escuela de Asistentes Sociales en Barcelona, dependiente de la Cátedra de Psiquiatría del Hospital Clínico, incorporando la atención a personas con trastorno mental al currículum profesional del Trabajo Social (Salcedo, 2011). A pesar de la ambigüedad inicial de esta figura profesional, la reconceptualización de la disciplina permitió que los y las trabajadores y trabajadoras sociales identificaran las problemáticas sociales asociadas a la enfermedad mental y establecieran los objetivos y actuaciones que debían ser propias del quehacer profesional. Finalmente, el desarrollo de la reforma psiquiátrica en España, tras la aprobación de la Ley General de Sanidad, afianzó los objetivos y funciones del Trabajo Social en salud mental, como eje de transformación social, dirigidos a la rehabilitación, reinserción social en la comunidad y recuperación centrada en la persona (Garcés, 2010).

Por tanto, como señalan Castañera et al. (2014), el Trabajo Social, dentro de los equipos interdisciplinares de salud mental, tiene como funciones específicas la atención integral y terapéutica de la persona con trastorno mental y su familia a través de acciones que favorezcan su plena inclusión en la comunidad. La práctica y la investigación desde el Trabajo Social deben estar enfocada hacia la prevención de los trastornos mentales y las situaciones de desamparo y exclusión social asociadas a la enfermedad, y la coordinación con las instituciones y recursos competentes en este ámbito. Todo ello, fomentando la participación y el empoderamiento de las personas y grupos sociales en su propio proceso, y en la búsqueda y promoción de recursos que favorezcan garantizar su bienestar. Asimismo, como indicaron los resultados de Khoury y Rodríguez (2015), los y las trabajadores/as sociales, desde su perspectiva y posición crítica, pueden facilitar una comprensión estructural del sistema de salud y abordar las barreras para el desarrollo de servicios y prácticas orientados a la recuperación. El estudio de Bjørkquist y Ramsdal (2021) sostiene que estas funciones, ante las barreras estructurales del sistema, hace que, en ocasiones estos/as profesionales traspasen los límites de su responsabilidad oficial para brindar más atención y ayuda a las personas que más lo necesitan, posicionando a los y las profesionales del Trabajo Social como colectivo de alto riesgo de sufrir burnout y angustia psicológica (Sánchez-Moreno et al., 2015).

1.2. La Cultura del Cuidado en Salud Mental

Los trastornos mentales implican disfunciones cognitivas, comportamentales y emocionales persistentes en el tiempo. La complejidad y persistencia de los síntomas de la enfermedad, en muchas ocasiones, provoca la existencia de un deterioro funcional que impide realizar actividades importantes para el día a día, como las relaciones interpersonales, higiene o el empleo. Esto posiciona a las personas con trastorno mental como población susceptible para la recepción de cuidado y asistencia a largo plazo (Aylaz & Yıldız, 2018).

Tradicionalmente, las personas con trastornos mentales graves eran atendidas en instituciones psiquiátricas. El movimiento de desinstitucionalización y los avances en medicamentos psicotrópicos implicó el cierre de los hospitales psiquiátricos y planteó la reinserción social de este colectivo en la comunidad (Reupert & Maybery, 2019). No obstante, los limitados recursos de atención crearon la necesidad de involucrar al sistema informal en el tratamiento y mantenimiento de la enfermedad. La familia asumió entonces el cuidado, afectando al bienestar y la adaptación de todos los miembros de la familia (Piñeiro et al., 2017).

1.2.1. Cuidado Familiar y Familismo como Recurso de Atención en Salud Mental

El cuidado formal de la salud mental ha estado siempre limitado. La mayoría de las personas con trastornos mentales de todo el mundo viven o tienen contacto habitual con sus familiares y dependen de ellos para recibir alojamiento, apoyo emocional y financiero, e incluso cuidado y seguimiento continuo en casos más graves (Donnelley & Murray, 2013). Sebern y Whitlatch (2007) documentaron que cuando una persona requiere atención debido a una enfermedad o discapacidad, tanto esta como su familia, prefieren que esa atención sea brindada por familiares o amistades cercanas.

El cuidado familiar hace referencia a la asistencia no remunerada que brindan las y los miembros de una familia a una persona enferma, asumiendo las consecuencias físicas y psicosociales que derivan de esa labor (Treichel et al., 2019). En las culturas mediterránea, latinoamericana y asiática, la unidad familiar se considera un pilar fundamental en la prestación de cuidados y se ha acuñado el término "familismo" al valor cultural que prioriza la conexión familiar (Vieira et al., 2019; Zhong et al., 2020). Este concepto ha evolucionado a lo largo de los años. Las primeras investigaciones conceptualizaron a la familia como una red privada que consistía en una familia nuclear que vive dentro de un hogar multigeneracional. En estudios posteriores la familia aparece como una red más extensa que incluye amistades, vecinos/as y miembros de la comunidad y enfatiza en las interacciones sociales cercanas y frecuentes que se dan entre todas las personas, independientemente del hogar (Katiria & Cruess, 2014; Keefe, 1984).

En la actualidad, el familismo está constituido por una fuerte identificación y apego familiar, sentimientos de interconexión, lealtad, reciprocidad, obligación familiar, apoyo mutuo y solidaridad entre los miembros de una familia (Mendez-Luck et al., 2016). Un estudio desarrollado por Hsiao et al. (2020b) en Taiwán concluyó que los miembros de la familia inevitablemente asumen las obligaciones de cuidar a las personas con problemas de salud mental debido a los valores culturales y las carencias del sistema de atención. En este aspecto, Rolland (2019) señala que las familias deben considerarse como un recurso esencial y socio colaborativo, tanto para las personas con trastorno mental como para los proveedores de atención médica. No obstante, las investigaciones realizadas informan que las familias se sienten mal equipadas para asumir roles de cuidadoras y necesitan apoyo para proteger su propia salud física y mental (Young et al., 2019; Rahmani et al., 2018).

A pesar de que el trastorno mental tiene un impacto en todos los miembros de la familia, la mayoría de las investigaciones sobre cuidado familiar se han centrado en la persona que ejerce el rol de cuidadora principal (Hopps et al., 2017). Como resultado de los valores tradicionales del patriarcado latente en la sociedad global, la mujer sigue siendo la figura central encargada de satisfacer las necesidades fundamentales y emocionales y velar por la salud física y mental de toda la familia. Numerosos estudios (Nihayati et al., 2020; Thara & Kamath, 2015) muestran que el 80% de quienes brindan atención a personas con trastornos mentales son mujeres. A pesar de que muchos estudios defienden que es mujer quien decide voluntariamente asumir este tipo de cuidado, los resultados del estudio cualitativo fenomenológico de Robelo-Zarza et al. (2020) sostienen que las mujeres asumen el rol de cuidadora por las condiciones sociales de género establecidas en la sociedad patriarcal, donde el hombre tiene la función de proteger y alimentar a su familia y la mujer debe al hombre obediencia y sometimiento, permaneciendo en la esfera privada y haciéndose cargo del cuidado del resto de miembros de la familia.

1.2.2. El Papel de las Asociaciones de Familiares y Personas con Trastorno Mental

Las asociaciones científicas y políticas gubernamentales han promovido la participación de las personas usuarias en varios aspectos de la asistencia sanitaria (Brett et al., 2014). El estudio realizado por Nordt et al. (2006) destaca que la participación de las personas con trastorno mental es un esfuerzo desafiante a causa del desequilibrio de poder entre profesionales y usuarios/as y el estigma asociado a la enfermedad que conduce a la exclusión social. No obstante, las organizaciones de personas con trastorno mental y familiares han liderado, junto a la familia, el cuidado de la salud mental.

En prácticamente todo el mundo, han aparecido movimientos antipsiquiatría y de defensa de los derechos humanos liderados por personas usuarias de los propios servicios de salud mental (Tanenbaum, 2011). Cazorla (2018) sostiene que estas entidades han sido tradicionalmente las encargadas de reivindicar derechos de dignidad y ciudadanía y exigir soluciones a la sistemática institucionalización de la enfermedad mental, la insatisfacción con las prácticas profesionales y la cuestionabilidad de la calidad de los recursos. A principios de la década de los 70, los llamados “supervivientes de la psiquiatría” comenzaron a organizarse para desafiar las actitudes y tratamientos opresivos existentes, influidos por el movimiento de los derechos civiles y la igualdad racial o el movimiento de las mujeres de Estados Unidos. Tras la desinstitucionalización psiquiátrica, las asociaciones de usuarios, usuarias y familiares fueron adquiriendo protagonismo y aumentando en número y visibilidad en foros profesionales (Adame, 2014).

El alcance de estos movimientos se realizó a nivel internacional, suponiendo así la creación de grandes entidades, tales como la Alianza Nacional de Enfermedades Mentales de Estados Unidos (NAMI por sus siglas en inglés), o la Federación Europea de Asociaciones de Familias de Personas con Enfermedades Mentales (EUFAMI por sus siglas en inglés) (Svettini et al., 2016; Steffen, 2011). En España, como recogen Ariño y San Pío (2007), el movimiento asociativo comenzó a constituirse en diferentes ciudades como alternativa o complemento a los servicios formales, ante la carencia de los recursos de atención en la comunidad. En 1983, se crea la Confederación Española de Agrupaciones de Familiares y Personas con Enfermedad Mental (FEAFES; actualmente, Confederación Salud Mental España) como organización estatal de representación del movimiento asociativo de familiares y personas con trastorno mental.

En la actualidad, la mayoría de las asociaciones de familiares y personas con trastorno mental, desempeñan su labor a nivel local desde entidades del tercer sector, con objetivos de apoyo mutuo, difusión de conocimientos, ocio y tiempo libre, sensibilización y defensa de los derechos del colectivo, y orientación laboral (López, 2020; Siles, 2016). A pesar de que estas asociaciones han sido poco estudiadas por la literatura científica, según Ostrow y Leaf (2014) son cada vez más reconocidas como componente indispensable de la red de atención a la salud mental. La revisión sistemática realizada por Roy et al. (2014) sostiene que el asociacionismo puede tener un impacto positivo en la recuperación y la autoestima de las personas. Según Siantz et al. (2019), estas entidades proporcionan oportunidades de respiro familiar a través de actividades específicas dirigidas a personas con trastorno mental que favorecen la convivencia familiar y palian la sobrecarga de las cuidadoras. En esta línea, Bauer et al. (2019) y Gillard (2015) destacan el importante papel de las asociaciones con jerarquías planas e igualitarias, construidas en entornos no estigmatizantes y basadas en enfoques participativos orientados a la recuperación, en la mejora de la calidad de vida y bienestar de las personas con trastorno mental y sus familias.

1.3. Sobrecarga en el Cuidado Familiar en Salud Mental

El cuidado familiar en salud mental ha sido objeto de estudio desde la década de los 50, donde autores y autoras como Treudley (1946), o Clausen y Yarrow (1955) trataban de evaluar las repercusiones de la reforma psiquiátrica en las personas con trastorno mental. Dicho interés aumentó tras la desinstitucionalización, cuando el papel de las familias en el cuidado se hizo más predominante. Desde entonces, numerosos estudios (Hegde et al., 2019; Rao et al., 2020) han demostrado que las familias que cuidan a personas con trastorno mental grave a menudo experimentan altos niveles de carga y niveles significativos de estrés derivados del cuidado. Seltzer et al. (1997) o Hassan et al. (2011) declaran que cuidar personas con trastornos mentales graves supone una carga más pesada que la que supone la atención y el cuidado de personas que tienen otro tipo de enfermedad o discapacidad.

Según Grandón et al. (2008), la carga familiar se refiere al impacto negativo de la enfermedad mental de una persona en la familia entera. Jagannathan et al. (2014)

diferencian dos tipos de carga -objetiva y subjetiva-. La carga objetiva se refiere a los retos cuantificables que enfrenta la familia y, más concretamente, la cuidadora, en el día a día. Entre ellos, el estudio de Alvarado et al. (2011) destaca la reducción del tiempo disponible, la alteración de las relaciones sociales, el incremento del esfuerzo y de las responsabilidades y los efectos negativos sobre la salud física, así como la reducción de la capacidad financiera, al atender económicamente a la persona cuidada o al tener que abandonar la ocupación laboral.

La carga subjetiva, sin embargo, hace referencia a los costes emocionales que enfrenta la familia como consecuencia de la enfermedad. Las cuidadoras pueden experimentar ira, sentimientos de culpa, miedo, desesperanza, tristeza y sentimientos y actitudes negativas hacia las personas enfermas (Durmaz & Okanlı, 2014). Weisman et al. (2018) o Onwumere et al. (2018) señalan que estos sentimientos pueden generar consecuencias más graves, tales como la angustia, la depresión, la ansiedad o trastornos por estrés postraumático. El estudio de Zauszniewski y Bekhet (2014) desarrollado con 60 mujeres cuidadoras de personas adultas que tenían un trastorno mental grave concluyó que el cuidado está relacionado con la angustia emocional y puede interferir en la socialización de la cuidadora principal, creando sentimientos de ira y resentimiento hacia la persona con enfermedad mental.

1.3.1. Factores Asociados a la Sobrecarga del Cuidado Familiar

No todas las cuidadoras experimentan los mismos niveles de carga derivados del cuidado. Investigaciones previas (Batista et al., 2015; Hsiao et al., 2020a; Koujalgi & Nayak, 2016) han informado de la existencia de múltiples diferencias sociodemográficas y clínicas asociadas a la carga del cuidado en salud mental. La mayoría de los estudios (Alzahrani et al., 2017; Ribé et al., 2018) revelan mayores niveles de carga y menor calidad de vida en cuidadoras mujeres, más jóvenes, con bajo nivel educativo, sin trabajo remunerado, con mala salud física y madres de la persona con trastorno mental. Una revisión realizada por Shah et al. (2010) observó mayores niveles de carga al cuidar a personas con trastorno mental en cuidadoras familiares que eran mujeres, más mayores, con menores ingresos económicos y apoyo social limitado. Un estudio reciente desarrollado en China con 355 cuidadoras familiares de personas con esquizofrenia mostró que los rasgos de personalidad, las estrategias de afrontamiento y la función familiar también influyen en la relación entre la carga de la cuidadora y la salud mental (Yu et al., 2019).

Las investigaciones correlacionan positivamente algunas características de la persona receptora de cuidados con mayores niveles de carga en cuidadoras (Peng et al., 2019). Los años de evolución de la enfermedad, la edad de inicio, el número de hospitalizaciones, el tipo de trastorno y el grado de discapacidad y dependencia son variables que se asocian con la sobrecarga familiar de la cuidadora principal (Cirici et al., 2018; Zanetti et al., 2018). El análisis multivariado realizado en el estudio de Detzel et al. (2015) halló que la gravedad e intensidad de los síntomas de la enfermedad, como aislamiento, conductas desorganizadas o dificultades para la comunicación, eran un importante predictor de la carga familiar.

Los hallazgos de Fekih-Romdhane et al. (2020) concluyeron que la depresión, la ira, el apoyo social -formal e informal- y ser cuidadora única eran los factores más importantes asociados a la carga del cuidado en salud mental. En el estudio de Maazinezhad et al. (2019), el apoyo social aparece como variable moderadora de las consecuencias negativas del desempeño del rol de la cuidadora, como un amortiguador del estrés y la sobrecarga. Los resultados de Lök y Bademli (2020) sugieren que el apoyo social tiene una relación positiva con una buena salud física y con el bienestar psicológico, así como la ausencia de depresión. MacCourt (2013) señala que las cuidadoras que cuentan con apoyo social probablemente brindarán una mejor atención a sus familiares, generarán ahorros en el sistema y mejorarán los beneficios adquiridos por el desempeño de cuidados. Por ello, la literatura considera preciso establecer vías de intervención de apoyo para luchar contra el aislamiento y la frustración de las cuidadoras. En esta línea, la revisión de Coulombe et al. (2018) halló que las intervenciones dirigidas a cuidadoras de personas con trastorno mental –psicoeducación y terapia– mejoran el apoyo social, y permiten el desarrollo de habilidades y estrategias de afrontamiento y de manejo del estrés. El modelo conceptual propuesto por Evans (2013) presenta el respiro familiar como instrumento de apoyo que, a través de medidas formales de asistencia práctica y financiera dirigidas a cuidadoras, reduce la carga de estas.

1.3.2. Barreras Culturales y Estructurales del Sistema: una Carga Añadida

La literatura ha analizado más recientemente el papel de los factores ambientales en la sobrecarga de la cuidadora. En la mayoría de los países del mundo, la cobertura de servicios y la protección financiera para las personas con trastornos mentales es limitada (Hanlon et al., 2019; Storm et al., 2019). El estudio desarrollado por Ebrahimi et al. (2018) identificó que la estructura de los sistemas de atención de todo el mundo, caracterizados por la falta de apoyos gubernamentales, la continua infrafinanciación de los servicios de salud mental y la ausencia o escasez de recursos de apoyo en el entorno clínico y en la comunidad, genera consecuencias adversas de estos trastornos en las familias. Deborah et al. (2020) sostienen que las políticas, los procedimientos y las prácticas empleadas en recursos sanitarios, son las encargadas de abordar adecuadamente estos desafíos para garantizar servicios de salud mental eficaces.

Por otro lado, Nurjannah et al. (2015) sostienen que el estigma es la barrera más importante para la provisión de políticas públicas de atención a la salud mental en relación con las implicaciones negativas para las personas con trastorno mental y su entorno. Multitud de estudios (Mascayano et al., 2020; Hasan & Musleh, 2017) han demostrado que estos estereotipos negativos son asociados frecuentemente a todos los miembros de la familia. Asimismo, existe una atribución pública de incompetencia que responsabiliza a la familia por la enfermedad de uno/a de sus miembros, conduciendo así a que experimenten sentimientos de culpa y vergüenza (Zisman-Ilani et al., 2013). Por ello, las investigaciones de Bonsu et al. (2020) o Girma et al. (2014) destacaron que el estigma asociado a la enfermedad mental se constituye como una potente fuente de angustia para las familias influyendo negativamente en la capacidad de estas para hacer frente a la labor que realizas.

Relativo a la educación como garantía de bienestar, Crescenza et al. (2021), señalan que las personas con discapacidad y necesidades educativas especiales se encuentran en desigualdad de condiciones en el acceso a las TIC. Las personas con trastorno mental son un colectivo afectado por esta cuestión. Un estudio longitudinal de Lee et al. (2013) informa que un buen ajuste a la educación de personas con trastorno mental grave previene de desigualdades y otras dinámicas de riesgo futuras.

1.3.3. Aspectos Positivos del Cuidado Familiar

En las últimas décadas, la investigación sobre el cuidado de personas con trastorno mental se ha centrado comúnmente en los efectos negativos del cuidado. Sin embargo, se ha prestado poca atención a los aspectos positivos del cuidado familiar. La literatura (Corona et al., 2017; Ran et al., 2016) considera el familismo y el cuidado familiar un factor protector crucial para el mantenimiento del completo bienestar y la satisfacción con la vida, especialmente en situaciones de crisis y angustia prolongada. Se ha relacionado frecuentemente con conductas positivas de autocuidado, adherencia a los tratamientos y manejo de la enfermedad. Los resultados de Campos et al. (2019) concluyeron que la satisfacción de cuidar puede jugar un papel importante la reducción del resto de dificultades.

En el estudio de Bauer et al. (2013) sobre las recompensas del cuidado de personas con trastorno mental en Alemania, las cuidadoras entrevistadas identificaron como factores positivos y de satisfacción, la intensificación y mejora de las relaciones familiares, las ganancias en carácter y experiencia de vida, y el reconocimiento por parte del familiar con enfermedad mental y del resto de miembros por el cuidado. Encontrar el sentido de la responsabilidad y la realización emocional también se han considerado aspectos positivos de este cuidado (Sahai et al., 2018). Para ello, según señala McCann et al. (2015) es necesario que las cuidadoras desarrollen estrategias de afrontamiento y la resiliencia para proteger su salud física y psicológica, mantener intencionalmente su propio bienestar y recibir apoyo social de otras personas para cuidar como un propósito y una satisfacción, ayudándolas a mantenerse en su función de cuidado.

1.4. La Salud Mental Global como Objetivo de Desarrollo Sostenible

Se calcula que los trastornos mentales afectarán a una de cada cuatro personas a lo largo de su vida. WHO (2017) estima que aproximadamente 450 millones de personas tiene un trastorno mental, siendo esta una de las principales causas de enfermedad y discapacidad en todo el mundo. De ellas, alrededor de 54 millones de personas cuentan con trastornos mentales graves, como esquizofrenia o trastorno afectivo bipolar, y 154 millones de personas sufren de depresión (Padmavati, 2012). En la actualidad, estos trastornos representan el 13% de la carga mundial de la enfermedad y se prevé que será del 15% en 2030 (Murray et al. 2012), principalmente debido a la naturaleza crónica e incapacitante de trastornos mentales comunes como la depresión, conductas adictivas o trastornos mentales graves como la esquizofrenia. Además, Vigo et al. (2016) destacan que los trastornos mentales contribuyen de manera sustancial e independiente a la carga de morbilidad en todo el mundo. Los trastornos mentales no solo pueden causar una alta y crónica discapacidad, sino que también tienen un alto impacto en la esperanza de vida de las personas (Lawrence et al. 2013).

A pesar de la alta prevalencia de estos trastornos en todo el mundo, el 70% de las personas que necesitan atención de salud mental carecen de acceso a servicios específicos de alta calidad. Según Collins et al. (2011), la complejidad y la limitada comprensión del cerebro y sus mecanismos contribuyen a la carencia de tratamientos efectivos y la escasez de intervenciones preventivas para los trastornos mentales. Además, cuando existen estos tratamientos generalmente no están disponibles para aquellos colectivos que más lo necesitan. La llamada “brecha de tratamiento en salud mental” se agrava en entornos de recursos limitados, como son los países de bajos y medianos ingresos (LMICs por sus siglas en inglés), los cuales representan una gran proporción de la carga mundial de enfermedad por estos trastornos (Wainberg et al., 2017).

El Movimiento por la Salud Mental Global (MGMH por sus siglas en inglés) surge en 2008 con el objetivo de cerrar la brecha de tratamiento para las personas que viven con trastornos mentales en todo el mundo. Este movimiento nace como una coalición de personas e instituciones comprometidas con la promoción de acciones basadas en la evidencia científica y los derechos humanos de las personas con trastornos mentales (Patel et al., 2011). En esta línea, ese mismo año, la WHO (2008) puso en marcha el Programa de Acción Global de Salud Mental (mhGAP por sus siglas en inglés) para reforzar el compromiso de los y las responsables políticos en la creación y mejora de políticas públicas de salud mental, la asignación de recursos financieros y humanos adecuados para la atención de los trastornos mentales, especialmente en LMICs, y lograr una mayor cobertura a través de intervenciones integrales. Estas iniciativas, así como la producción de evidencia científica generada de ellas, han demostrado que la prevención y el tratamiento efectivo de los trastornos mentales es posible, alimentando así la necesidad de incluir la salud mental como objetivo global de desarrollo (Patel et al., 2016).

La salud mental ha sido durante mucho tiempo una prioridad baja en el desarrollo. A pesar del éxito de los Objetivos de Desarrollo del Milenio (en adelante, ODM) en reducir la brecha general de salud entre los países de altos y bajos ingresos y los logros alcanzados para enfermedades infecciosas como la malaria o el VIH/SIDA, los ODM nunca han incluido ninguna referencia a la salud mental (Votruba et al., 2016). Diversos estudios (Patel et al., 2018) consideran que la salud mental debe considerarse como un bien público global notorio para todos los países, independientemente del desarrollo económico de cada uno. La WHO (2011) y autores/as como Gureje y Jenkins (2007) defienden que la salud mental es un requisito transversal a otros factores de desarrollo como la salud física, la educación, la justicia, el empleo y el desarrollo económico. La salud mental desempeña un papel clave en la lucha contra la exclusión social y la desigualdad, y en los esfuerzos por lograr la cobertura sanitaria universal, el acceso a la justicia, el respeto a los derechos humanos y el desarrollo económico sostenible.

Durante la última década, los trastornos mentales sí se han reconocido cada vez más como problemas de desarrollo global (Eaton et al., 2014) y la comunidad internacional (Izutsu et al., 2015; Thornicroft & Patel, 2014) ha reivindicado que el desarrollo sostenible no puede lograrse sin la inclusión de la salud mental como una prioridad mundial clave. Finalmente, la Agenda 2030 para el Desarrollo Sostenible, adoptada por todos los Estados Miembros de las Naciones Unidas en 2015 incorporó la salud mental, de manera específica o transversal, dentro de los 17 nuevos Objetivos de Desarrollo Sostenible (SDG por sus siglas en inglés) (WHO, 2015):

- **SDG 3.4.** Para 2030, reducir en un tercio la mortalidad prematura por enfermedades no transmisibles a través de la prevención y el tratamiento y promover la salud mental y el bienestar.
- **SDG 3.5**. Fortalecer la prevención y el tratamiento del abuso de sustancias, incluido el abuso de estupefacientes y el uso nocivo del alcohol.
- Otros SDGs -especialmente 1, 5, 8 y 10- relacionados con la reducción de la pobreza, el género, el desarrollo económico y la reducción de las desigualdades

respectivamente, están vinculados de manera transversal a la salud mental, puesto que los trastornos mentales están estrechamente ligados con la pobreza y la exclusión social (Patterson et al. 2020).

Según Herrman (2019), para alcanzar dichos objetivos y mejorar la salud mental global, los SDG deben enfocarse hacia la mejora de la dotación de recursos de salud mental, el abordaje de los desafíos y barreras presentes en la atención, el desarrollo e implementación de políticas públicas, la adopción de nuevas tecnologías, la mejora de la dotación presupuestaria, así como el fomento de la investigación e innovación de la salud mental, todo ello considerando la salud mental como un componente esencial en la cobertura universal de salud. Aunque es un paso positivo, continúan existiendo desafíos significativos dada la carga de enfermedad y la brecha de tratamiento, así como la estigmatización generalizada de este colectivo, la discriminación y las violaciones de los derechos humanos contra las personas con trastorno mental (Cratsley & Mackey, 2018).

CAPÍTULO 2. OBJETO Y OBJETIVOS DE INVESTIGACIÓN

2.1. Justificación del Objeto de Estudio

Los trastornos mentales son comunes en la población general y están asociados con niveles altos de estigma, discapacidad y dependencia, que contribuyen significativamente a la carga de la enfermedad. Las enfermedades mentales -especialmente los trastornos mental graves- generan elevados índices de angustia y conducen a la pérdida de la calidad de vida, el desgaste económico y la disfunción social de la persona (Sahithya & Reddy, 2018). A medida que las políticas de atención a la salud mental se han alejado de la institucionalización, la mayoría de las responsabilidades de cuidado de las personas con trastorno mental han recaído sobre el sistema informal (Quinlan et al., 2018). Según Lippi (2016), en la mayoría de los países del mundo, la familia se ha consolidado como principal sistema de apoyo, experimentando la carga derivada de proporcionar atención, y mermando la capacidad de cuidar y reduciendo su propio bienestar.

El impacto de este cuidado ha sido considerablemente discutido en la literatura internacional e incluye implicaciones físicas, sociales, emocionales y financieras (Happell et al., 2017). El análisis de la realidad elaborado en el capítulo anterior permite observar los factores determinantes de la sobrecarga en cuidadoras familiares de personas con trastorno mental. No obstante, no es posible entender el cuidado familiar de la salud mental, sin tener en cuenta los múltiples factores de vulnerabilidad que rodean la propia enfermedad.

Las barreras económicas, sanitarias, culturales y sociales inherentes a la atención y el tratamiento de la salud mental son causa y, a su vez, consecuencia, del uso de la familia como recurso alternativo de cuidado y de la carga que esta tarea genera para garantizar el bienestar y la integración de las personas con trastorno mental (Akbari et al., 2019; Ebrahimi et al., 2018). Esta tesis doctoral se enfrenta, por tanto, al cuidado familiar de personas con trastorno mental como objeto de estudio transversal que implica no únicamente a las repercusiones negativas y los factores asociados a las cuidadoras, sino también al ejercicio y quehacer profesional y a las políticas públicas y sistemas de atención a la salud mental global.

La mayoría de los estudios que analizan el cuidado familiar de la salud mental se han centrado únicamente en evaluar las variables sociodemográficas y clínicas de las personas que ejercen el cuidado y las personas cuidadas y su relación con la sobrecarga (Mashudi et al., 2019; Yildirim et al., 2017). No se han hallado estudios que analicen de una manera integral y holística la temática presentada, incorporando las variables estructurales y ambientales que hostilizan el cuidado. Sánchez-Moreno y Barrón (2003) defienden un modelo de salud mental que debe tener en cuenta las influencias tanto psicológicas como socioestructurales sobre el bienestar de las personas. De esta manera, la literatura consultada conduce a diferenciar dos agrupaciones que podrían ser categorizadas como "barreras asociadas al cuidado familiar de la salud mental", que incluye factores individuales asociados a la cuidadora y persona cuidada y factores asociados a los sistemas de atención. Esta clasificación responde a la categorización propuesta por Corrigan et al. (2014) sobre barreras del estigma para la búsqueda de ayuda, pero vinculada al objeto de esta investigación.

2.2. Posicionamiento de Investigación

2.2.1. El Paradigma de la Recuperación en Salud Mental desde el Trabajo Social: Aplicaciones para este Estudio

La recuperación se ha convertido en la orientación establecida dentro de la política y la provisión de atención a la salud mental a nivel nacional e internacional. A pesar de que la investigación en este ámbito continúa centrándose con frecuencia en los aspectos biomédicos de la enfermedad, los modelos orientados hacia valores y principios de recuperación y participación de la persona han adquirido protagonismo en el estudio de los trastornos mentales, conduciendo a un aumento de la evidencia de las precariedades y necesidad de cambio en los elementos de la atención de la salud mental y sirviendo de guía para el desarrollo organizativo de los servicios (Waldemar et al., 2016; Neil et al. 2013). Esta investigación no apoya la suposición de cronicidad de los trastornos mentales y, siguiendo a Kerman y Kidd (2020), defiende que es posible alzanzar una vida satisfactoria a través de la reducción y manejo de los síntomas, la comprensión de la enfermedad y la potenciación de las capacidades de la persona. Por ello, este estudio considera que garantizar la recuperación de la persona es crucial para mejorar la calidad de vida de las personas con trastorno mental y de sus familias y disminuir la carga de las personas que ejercen el cuidado familiar.

Como señalan Juvva y Newhill (2011), el paradigma de la recuperación de la salud mental, no únicamente supone la recuperación de la vida y las capacidades mermadas por la enfermedad, sino también implica de la recuperación de la imagen que la sociedad tiene de los trastornos mentales y las barreras estructurales que derivan de la misma. En este sentido, los agentes implicados en este estudio -personas con trastorno mental, cuidadoras, profesionales y los propios sistemas de atención- no son meramente objetos de estudio, sino que se posicionan como elementos de transformación de la realidad desde un enfoque de salud mental comunitaria e inclusiva.

El Trabajo Social y la atención de la salud mental han evolucionado considerablemente en las últimas décadas. Carpenter (2002) sostiene que la profesión ha ofrecido una contribución incalculable a este campo y que, a su vez la salud mental ha ayudado a definir la práctica del trabajo social y la razón de ser de la profesión. Esta tesis doctoral se apoya en el movimiento de reconceptualización del Trabajo Social como símil al movimiento de recuperación en salud mental, como modelos comunitarios de lucha por los derechos humanos y la transformación social de la realidad.

2.2.2. Posiciones Metodológicas

Los paradigmas que guían esta tesis doctoral se adscriben a fundamentos pragmáticos (Aune, 1970; Murphy & Ricard, 1990), que se alejan del dualismo tradicional de objetividad y subjetividad, para dar una visión integral del objeto de estudio (Tashakkori & Teddlie, 1998). El pragmatismo defiende que la misión de la ciencia no es encontrar la verdad absoluta, sino facilitar la resolución de los problemas sociales. Para ello, como señala Wahyuni (2012), esta corriente acepta una mezcla de la ontología, epistemología, axiología y metodología de los diferentes paradigmas para abordar y comprender los fenómenos sociales.

Cabe destacar que este estudio cuenta con fuertes influencias de la teoría crítica, la cual permite tener una visión holística y dialéctica del problema, buscando generar una transformación de las estructuras sociales, basada en la lucha contra la desigualdad y la liberación de las personas que conforman el contexto social de investigación (Ramos, 2015). La convergencia de pragmatismo y crítica en esta tesis doctoral refuerzan un diseño abierto que se reconstruye en base a los resultados obtenidos a medida que avanza la investigación, y que pretende desenmascarar, desde diferentes perspectivas, las barreras asociadas al cuidado familiar de personas con trastorno mental, analizando el papel del contexto histórico, individual, social, cultural, económico y familiar.

El pragmatismo ha sido aclamado como el mejor paradigma para justificar el uso de la investigación con métodos mixtos. Siguiendo a Creswell (2015), este enfoque utiliza datos cuantitativos y cualitativos, integra los dos, y, posteriormente, dibuja interpretaciones basadas en las fortalezas de ambos conjuntos de datos para comprender el fenómeno de investigación. Este estudio va más allá de la combinación única de estas dos perspectivas, e incluye la revisión sistemática como metodología cualitativa que ofrece una visión más completa y crítica del problema de investigación (Lodhi, 2016). Por tanto, en esta tesis doctoral, la triangulación de metodologías cuantitativas y cualitativas permiten ofrecer una comprensión unificada de las barreras asociadas al cuidado familiar de personas con trastorno mental, enriqueciendo así la complejidad y calidad de los resultados de investigación.

Una de las características definitorias del pragmatismo es la flexibilidad en los procesos de investigación (Hunter & Brewer, 2015). Por ello, esta investigación de métodos mixtos es el resultado de un diseño de investigación flexible, emergente y progresivo que permite redefinir el objeto, objetivos y las estrategias durante el proceso de estudio en función de los hallazgos obtenidos. De este modo, los resultados de los estudios cuantitativos[2] instaron a la realización de un estudio cualitativo[3] que permitiera analizar la percepción profesional sobre el cuidado familiar y la gestión de las políticas públicas. Consecuentemente, las conclusiones generadas a partir de los tres primeros estudios derivaron en la necesidad de realizar una revisión sistemática[4] sobre el cuidado familiar en salud mental para identificar las brechas y barreras de los sistemas de atención.

Para aplicar las técnicas de investigación que involucran la participación de seres humanos, se asumió un procedimiento ético-responsable siguiendo los valores éticos

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[2] Artículos 1 y 2
[3] Artículo 3
[4] Artículo 4

promulgados en la Declaración de Helsinki por la Asociación Médica Mundial (World Medical Association, 2013). Por ello, se obtuvo el consentimiento ético de todas las personas participantes, garantizando los derechos a la información, protección de datos personales y garantías de confidencialidad, no discriminación, gratuidad y posibilidad de abandonar el estudio en cualquiera de sus fases.

2.2.3. La Influencia de la Formación en los Enfoques de Investigación

La modalidad de esta tesis doctoral, basada en el compendio de publicaciones científicas, permite el abordaje y la triangulación de estas técnicas de recolección y análisis de datos durante el proceso de investigación. Cada una de las publicaciones que se presentan en los siguientes capítulos corresponden a una metodología, objetivo y visión del problema a estudio, e incumbe a las competencias adquiridas por la doctoranda en las diferentes fases del proceso de formación.

Al inicio de la tesis doctoral, la utilización de instrumentos de evaluación y herramientas de análisis de datos cuantitativos que habían sido previamente manejados, tales como la escala Zarit Burden Inventory o el paquete informático SPSS, fueron cruciales para iniciar el ciclo y comprender las prácticas de publicación. Los resultados del primer estudio permitieron centrar dirigir la investigación hacia una mirada más amplia y realista del objeto de estudio.

Algunos programas de doctorado han comenzado a mirar más allá de la disertación como la única forma de demostrar la competencia del estudiantado. Diferentes autores y autoras (Senior et al., 2020; Pardun et al., 2015) sostienen que la formación durante el doctorado y la colaboración en otros proyectos de investigación fortalecen las habilidades y capacidades individuales para afrontar nuevas metodologías de investigación. En este caso, los entrenamientos a partir de la formación en técnicas de investigación cualitativa, así como la participación en otras investigaciones, fortificaron los conocimientos y las competencias profesionales y académicas de la doctoranda para enfrentar un estudio cualitativo a nivel nacional que permitiera una asociación de variables y categorías de estudio, prevalencia y categorización de las características y barreras del modelo de salud mental y las responsabilidades del cuidado para la familia.

Badley (2009) sostiene que la creciente independencia y el aprendizaje autónomo también son elementos esenciales para evaluar la formación doctoral. Según Wisker (2012), los y las estudiantes de doctorado deben ser capaces de emprender nuevos desafíos que puedan ser resueltos con total autonomía bajo mínima supervisión de los y las directores. En esta línea, la última fase de la presente tesis doctoral incluye el desarrollo de una revisión sistemática que proporciona una comprensión más integral los desafíos y barreras en los sistemas de salud mental y su impacto en la familia, y que supuso un enorme reto de investigación y publicación para la doctoranda.

2.3. Objetivos de Investigación

2.3.1. Prioridades de Investigación en Salud Mental y Cuidado Familiar

La literatura científica enfatiza la necesidad de reforzar el liderazgo y la gobernanza de la salud mental, proporcionar servicios integrales adecuados y comunitarios, implementar estrategias de promoción y prevención, y fortalecer los sistemas de información y la investigación sobre la salud mental (Kristensen et al., 2019; Petersen et al. 2017). Thornicroft et al. (2012) señalan que la investigación en salud mental tradicionalmente se ha descuidado y ha sido infrafinanciada, especialmente en países de bajos y medianos ingresos (LMICs por sus siglas en inglés). Para potenciar la investigación en este campo, Hazo et al. (2019) y Mei et al. (2020) defienden que no solo es necesario aumentar la financiación, sino también desarrollar la capacidad investigadora y crear entornos de investigación viables.

La investigación en salud mental se ha llevado a cabo desde diferentes niveles y disciplinas, como la psiquiatría, la neurociencia, la psicología, la epidemiología o las ciencias sociales, entre otras, aunque tradicionalmente ha predominado la investigación desde la psiquiatría biológica o farmacológica (Van Os, 2012). Collins et al. (2011) ya señalaron que la investigación en salud mental no debe realizarse únicamente desde la clínica, sino que debe explorar el papel de los contextos psicológicos, socioculturales y ambientales. La investigación desde las ciencias sociales ha adquirido un papel significativo en el análisis del entorno social y cultural como factores de riesgo y protección asociados a los trastornos mentales (Eack, 2017).

En los últimos años, se han puesto en marcha manifiestos y propuestas de agendas de trabajo tratando de encaminar o reconducir las políticas, prácticas y prioridades de investigación en salud mental de todo el mundo. La participación de usuarios, usuarias y familiares en las propuestas de investigación ha adquirido un peso relevante en la agenda de investigación general, la política y las directrices de muchos países, especialmente en países de altos ingresos (HICs por sus siglas en inglés) (Kleintjes et al., 2010; Veseth et al., 2017). Boote et al. (2002) y Fulford y Wallcraft (2009) defienden que esta inclusión conduce al diseño e implementación de estudios de mayor calidad y relevancia debido a la perspectiva única que los y las consumidores/as pueden aportar a un proyecto de investigación desde primera persona.

En esta línea, la iniciativa James Lind Alliance y el proyecto ROAMER (A Roadmap for Mental Health Research in Europe) desarrollado en Reino Unido para la investigación en salud mental en Europa han incluido a más de 1.000 usuarios, usuarias, familiares, profesionales y otras partes interesadas en el establecimiento de prioridades a gran escala para la investigación de trastornos específicos y salud mental general. Los resultados del proyecto, publicados en múltiples publicaciones científicas (Forsman et al., 2015; Robotham et al., 2016; Wykes et al., 2015), identifican seis áreas prioritarias para la investigación de salud pública en el campo de la salud mental de los próximos 10 años -infraestructuras y desarrollo de capacidades, biomedicina, investigación y tratamientos psicológicos, problemas sociales y económicos, salud pública y bienestar- que incluyen de manera transversal la importancia de la familia y del cuidado familiar.

Tabla 1

Prioridades de investigación en salud mental pública europea según las recomendaciones del proyecto ROAMER

Objetivo	**Desafíos de investigación**
Prioridad 1. Identificar causas, riesgos, factores protectores y salutogénicos y procesos para la salud mental a lo largo de la vida	P1.1. Fortalecer la comprensión de los factores culturales relevantes para la salud mental pública.
	P1.2. Realizar y mantener estudios de cohorte prospectivos a largo plazo para investigar los determinantes de la salud mental y el bienestar y estudiar los factores de riesgo y protección para los trastornos mentales y los comportamientos suicidas.
	P1.3. Fortalecer la investigación a lo largo de la vida con respecto a las ventanas de tiempo sensibles del desarrollo humano, incluidos los factores salutogénicos ambientales y de desarrollo pertinentes a la salud mental pública.
	P1.4. Fortalecer la investigación sobre la influencia de las familias, las políticas públicas y los servicios en la salud mental a lo largo de la vida, especialmente de niños, niñas y adolescentes.
	P1.5. Fortalecer la comprensión de los vínculos entre las enfermedades físicas y mentales, y sus implicaciones para los servicios.
Prioridad 2. Avanzar en la implementación de intervenciones públicas efectivas de salud mental	P2.1. Desarrollar evaluaciones sistemáticas, incluida la utilización de experimentos naturales.
	P2.2. Identificar o desarrollar medidas de resultado intermedias que sean predictivas de resultados a largo plazo y que puedan usarse como medidas indirectas en estudios de intervención donde los resultados a largo plazo son difíciles de medir
	P2.3. Fortalecer la investigación sobre la implementación, difusión y sostenibilidad de la promoción de la salud mental, la prevención de los trastornos mentales y las intervenciones de prestación de servicios.
	P2.4. Desarrollar enfoques participativos apropiados para la evaluación de intervenciones complejas de salud mental pública.
	P2.5. Fortalecer la investigación sobre nuevos enfoques y tecnologías para la promoción de la salud mental, la prevención de enfermedades y la prestación de servicios de salud mental.

	P2.6.	Fortalecer la investigación sobre la eficiencia y la calidad de los sistemas de salud mental y las intervenciones orientadas a la comunidad, utilizando ensayos controlados aleatorios y otros diseños de investigación de alta calidad.
	P2.7.	Fortalecer la investigación sobre los marcos para lograr una atención efectiva de la salud mental a nivel organizacional, gerencial y clínico.
Prioridad 3. Aumentar la equidad y reducir las disparidades en la salud mental	P3.1.	Fortalecer la investigación sobre la salud mental de grupos desfavorecidos, poblaciones marginadas y poblaciones en riesgo.
	P3.2.	Fortalecer la investigación sobre la promoción de la salud mental en todas las políticas.
	P3.3.	Fortalecer la investigación sobre la protección de los derechos de las personas con problemas de salud mental.

Fuente: Elaboración propia a partir de las recomendaciones del proyecto ROAMER

En línea con estas recomendaciones, los resultados del estudio realizado por el comité de investigación de la Association of Community Health Nursing Educators (2010) incluyeron como prioridad de investigación en salud pública el cuidado familiar y la salud mental, y la necesidad de un enfoque cooperativo entre entornos académicos y prácticos. El avance de la investigación para apoyar mejor las necesidades de las cuidadoras familiares se ha convertido, en los últimos años, en un área de creciente énfasis a nivel internacional. Una investigación reciente desarrollada por Harvath et al. (2020), en la cual participaron 50 investigadores e investigadoras, defensores políticos y financiadores y otros expertos/as en instituciones de cuidado del ámbito público y privado, establecieron 10 prioridades de investigación sobre cuidado familiar, aplicables a campos como la salud mental:

PCF.1. Evaluar tecnologías que faciliten la elección y la toma de decisiones compartida.

PCF.2. Determinar dónde se integra mejor la tecnología en la trayectoria de la prestación de cuidados.

PCF.3. Evaluar intervenciones adaptativas centradas en la familia a través de condiciones, situaciones, etapas, necesidades, preferencias y recursos.

PCF.4. Examinar la heterogeneidad de actitudes, valores y preferencias hacia la prestación de cuidados, servicios y apoyos.

PCF.5. Evaluar las intervenciones de las cuidadoras familiares de manera que aborden la complejidad, traducción, escalabilidad y sostenibilidad del mundo real.

PCF.6. Desarrollar un marco conceptual y una tipología de la trayectoria del cuidado para nuevas intervenciones y resultados.

PCF.7. Realizar una evaluación de riesgos / necesidades de las necesidades cambiantes de las cuidadoras familiares a lo largo de la trayectoria de la prestación de cuidados.

PCF.8. Llevar a cabo una investigación de implementación de programas de cuidados basados en evidencia para poblaciones diversas.

PCF.9. Desarrollar medidas de resultado que sean relevantes para las cuidadoras de diversos grupos sociales y culturales.

PCF.10. Desarrollar metodologías de investigación que den cuenta de las complejas estructuras del cuidado familiar.

A pesar de los esfuerzos por establecer estas prioridades, los estudios sobre cuidado familiar en salud mental en personas adultas y la carga que asumen las familias se ha reducido en los últimos años. El impacto de la prestación de cuidados en salud mental ha sido una temática bien documentada, no obstante, la familia todavía encuentra barreras estructurales, limitaciones de financiación y discriminación dentro del propio sistema de salud que merma su propio bienestar (Morrison & Stomski, 2019).

Estas prioridades de investigación están destinadas a servir como una hoja de ruta para el desarrollo de estudios que aborden las brechas más relevantes en el campo del cuidado familiar en salud mental. Entre estas prioridades, se destaca la insistencia de expertos y expertas en emplear metodologías de investigación que cumplan parámetros e indicadores de calidad científica, como son las revisiones sistemáticas. Hurley et al. (2020) o Quinlan et al. (2020) consideran que es ineludible el desarrollo de estudios que analicen el cuidado familiar en salud mental desde una perspectiva holística que incluya diferentes visiones del problema. Esto es necesario para ayudar a los y las profesionales de la salud mental a brindar atención psicosocial eficaz a las cuidadoras y las partes interesadas de la comunidad (Ahmed et al., 2018).

2.3.2. Objetivos del Estudio Actual

De acuerdo con las prioridades de investigación en salud mental P14, P21, P26, P27 y las prioridades de investigación PCF4, PCF7 y PCF10 sobre cuidado familiar señaladas anteriormente, la finalidad principal de esta tesis doctoral es conocer de manera integral las barreras asociadas al cuidado familiar de la salud mental utilizando metodologías de alta calidad científica.

Para hacer operativa la finalidad de la investigación de una manera más sencilla y siguiendo las recomendaciones de la literatura expuestas en los apartados anteriores, la presente tesis doctoral plantea tres objetivos generales y siete objetivos específicos. Los objetivos del estudio fueron surgiendo a medida que avanzaba la investigación.

Objetivo general 1.

Explorar los factores asociados a la sobrecarga de las cuidadoras familiares de personas con trastorno mental

Objetivos específicos

OE 1. Analizar las variables sociodemográficas y clínicas de las cuidadoras y de las personas cuidadas

OE 2. Identificar la relación entre las variables sociodemográficas y clínicas que definen a la cuidadora y la sobrecarga

OE 3. Establecer las variables que predicen la sobrecarga en cuidadoras familiares de personas con trastorno mental.

Objetivo general 2.

Conocer la percepción de los profesionales de la salud mental sobre el cuidado familiar y la gestión de las políticas públicas en este ámbito

Objetivos específicos

OE 4. Identificar las variables de estudio para conocer el alcance de la responsabilidad del cuidado familiar en salud mental

OE 5. Explorar las barreras estructurales del modelo de salud mental desde una perspectiva psicosocial profesional.

Objetivo general 3.

Analizar los desafíos y barreras de los sistemas de atención a la salud mental y su impacto en la familia

Objetivos específicos

OE 6. Sintetizar la literatura científica sobre las políticas públicas de atención a la salud mental y su impacto en la familia

OE 7. Estudiar las características y la eficacia de las políticas de atención a la salud mental y su impacto en el bienestar y calidad de vida de las personas con trastorno mental y sus familiares.

CAPÍTULO 3. MATERIAL Y MÉTODOS

3.1. Producción Científica en la Investigación en Ciencias Sociales

La producción científica se define como la parte materializada del conocimiento generado a partir de las actividades académicas y científicas del personal investigador. Generalmente, la literatura vincula la producción científica con la creación de nuevo conocimiento a través de publicaciones (Iaria et al., 2018; Coura & Willcox, 2003). No obstante, Schöpfel y Farace (2010) defienden que la literatura gris (tesis doctorales no publicadas, participación en congresos y reuniones científicas, participación en actividades de I+D, clases magistrales) o el trabajo de campo también son partes sustanciales de la producción científica. Para autoras como Amelia y Rahmaida (2017), el principal indicador de producción científica es la transferencia de resultados de investigación en forma de publicaciones científicas en revistas o editoriales de impacto.

3.1.1. La Publicación Científica en Revistas de Impacto: Indicadores de Calidad y Desempeño Académico

En el seno de una sociedad académica neoliberal, basada en el mercado y la competencia, la publicación de artículos científicos se ha convertido en una actividad esencial y un elemento imprescindible en las acreditaciones a figuras docentes e investigadoras, y tiene un impacto en la clasificación de las instituciones de investigación (Gasparyan, 2010; Macfarlane, 2019). No obstante, el ansia generalizada de publicación ha provocado un aumento visible del fraude científico, el cual afirma que tanto el sistema y la integridad de la investigación, como el funcionamiento de la ciencia están en crisis. Los estudios de Steneck (2006) o Horbach y Halffman (2017), sugieren que la manipulación de datos, las autocitas editoriales, el plagio, las prácticas de investigación cuestionables o el desarrollo de estudios irreproducibles, son las malas prácticas científicas más presentes en la actualidad. En esta línea, numerosos estudios han analizado la importancia de examinar los métodos de evaluación de la calidad de la investigación, poniendo especial énfasis en la revisión por pares, el número y calidad de las citas recibidas o el factor de impacto de las revistas científicas, como medios para prevenir la mala conducta en la ciencia (Begley & Ioannidis, 2015; Huang, 2016; Nayak, 2019).

Para Miholič y Južnič (2018), publicar en revistas académicas de renombre internacional garantiza el éxito del trabajo de investigación. Akers (2019) señala que la reputación de estas viene condicionada por el prestigio de los editores, editoras o instituciones afiliadas, las estrategias de difusión o el rigor en los procesos de revisión por pares. Este último se considera un garante subjetivo esencial de la calidad de la investigación. Algunos autores y autoras (Stroebe et al., 2012; Pontille & Torny, 2015) señalan que el sistema de revisión por pares tiene la responsabilidad de salvaguardar la integridad de la ciencia y promover contribuciones teóricas o prácticas confiables, relevantes y valiosas. Los revisores y revisoras tienen la función de garantizar esto comprobando la rigurosidad y transparencia de los métodos de investigación empleados (Aguinis et al., 2018). No obstante, la literatura (Kepes & McDaniel, 2013; Smaldino & McElreath, 2016) informa de la existencia de desafíos en el sistema actual de revisión por pares, tales como la rigurosidad en el proceso, la profesionalidad de la revisión o el estímulo de prácticas de investigación cuestionables, como es la eliminación de resultados no significativos. En esta línea, los resultados del estudio de Köhler et al. (2020) sugieren un marco de competencia para la revisión que define los comportamientos críticos que son necesarios para una buena revisión con el objetivo de capacitar formalmente a revisores y revisoras y mejorar la práctica de revisión para que esta sea la piedra angular sobre la que se construya el avance de la ciencia.

Sin embargo, la clasificación más objetiva de estas revistas generalmente se ha realizado a través de indicadores bibliométricos, utilizando portales, índices y métricas objetivas que evalúan la calidad de los productos de investigación (Nessi et al., 2020). La indexación de las revistas en bases de datos nacionales e internacionales o la frecuencia con la que se citan sus artículos en otros artículos de revistas, permite analizar, comparar, y evaluar la productividad científica de instituciones e investigadores/as. En la actualidad y a pesar de sus numerosos retractores (Moustafa, 2015), el factor de impacto de una revista (JIF) es el indicador más sólido y condiciona a las personas investigadoras a decidir dónde enviar sus manuscritos para su publicación y a los potenciales revisores, revisoras y editores/as a decidir donde evaluar (Akers, 2019; Sugimoto & Larivière, 2018). El JIF es un índice sistemático y objetivo diseñado por Garfield (2006) del Institute of Scientific Information (ISI), que define el reconocimiento científico de una revista a través de la evaluación de la calidad de las citas recibidas. El estudio de Brito y Rodríguez-Navarro (2019) asoció que las publicaciones en revistas con índices de impacto altos estaban asociadas con una alta calidad científica.

Estas métricas de prestigio se calculan a partir de sofisticados algoritmos matemáticos similares al PageRank, utilizado para clasificar la importancia de las páginas web basándose en los buscadores de Google (Page et al., 1999). Un grupo de investigadores e investigadoras de la Universidad de Washington desarrolló un algoritmo similar para la evaluación de la influencia de las revistas científicas incluidas en la Web of Science (WoS) de Clarivate Analytics -anteriormente Thomson Reuters- compuesto por Science Citation Index Expanded (SCIE), Social Sciences Citation Index (SSCI), y Arts & Humanities Citation Index (AHCI). Este JIF aparece anualmente en el Journal Citation Reports (JCR) y evalúa el impacto y relevancia de las principales revistas científicas del área de las ciencias sociales y aplicadas. En la actualidad, está considerado, como el "estándar de oro" para el análisis de citas y en la evaluación científica (Harzing & Alakangas, 2016; Saeed et al., 2019).

Del mismo modo, un grupo de investigación de la Universidad de Granada desarrolló el indicador SCImago Journal Rank (SJR) para evaluar la calidad de las revistas científicas, aplicando el algoritmo PageRank en la base de datos Scopus, producto de Elsevier (González-Pereira et al., 2010). Como señalan estos autores, a diferencia de JCR, el SJR no solo valora la cantidad de citas recibidas, sino que asigna ponderaciones a las citas bibliográficas en función de la importancia de las revistas que las emitieron, evaluando así la combinación de la cantidad y la calidad de las citas recibidas por la revista.

Además de estos indicadores, la literatura destaca el uso del índice *h* propuesto por Hirsch (2005). A pesar de las críticas que tradicionalmente ha recibido este indicador (Bar-Ilan, 2008), algunos estudios señalan que es el método más preciso para medir la calidad científica y evaluar la producción actual y pronosticar el desempeño científico futuro, puesto que combina la productividad de la persona investigadora y el impacto de la revista (Kulasegarah & Fenton, 2010; Roldan-Valadez et al., 2019). El índice *h* más conocido es un producto de Google que ofrece un índice de impacto de las revistas científicas, medido a partir del recuento de citas en Google Académico (Teixeira, 2018).

Un estudio longitudinal desarrollado por Harzing y Alakangas (2016) mostró que las tres bases de datos mencionadas y sus respectivos algoritmos matemáticos proporcionan suficiente consistencia y estabilidad de cobertura para ser utilizados como indicadores de calidad científica, aunque existen otras múltiples métricas para conocer la calidad de las revistas y publicaciones científicas. En contraposición, numerosos estudios (Chapman & Ellinger, 2019; McKinnon, 2017) puntualizan en las limitaciones que supone la dependencia de estas clasificaciones para evaluar la ciencia ya que pueden sesgar el cuerpo teórico y la idiosincrasia de la investigación académica.

3.1.2. Fronteras para la Publicación Científica de la Investigación en Ciencias Sociales

Las materias asociadas con las ciencias naturales -Ciencia, Tecnología, Ingeniería y Matemáticas- han liderado la producción científica desde la Segunda Guerra Mundial y el surgimiento de la llamada “Big Sciencie” (Price, 1986), provocando el crecimiento de disciplinas métricas de la información para evaluar el impacto científico de la investigación, como la bibliometría, cienciometría o infometría (De Bellis, 2009). Rosario et al. (2017) sostienen que el desarrollo y la evaluación de la producción científica en Ciencias Sociales difiere respecto a otras áreas del conocimiento, debido al tardío desarrollo científico de las disciplinas y las particularidades de su investigación.

La revisión realizada por Nederhof (2006) sintetiza una serie de características de la investigación en Ciencias Sociales que limitan la producción científica de impacto. En primer lugar, la investigación en Ciencias Sociales comúnmente se realiza a nivel nacional o regional y, por tanto, la producción está orientada principalmente a un público local. Esto supone una frontera de investigación internacional que imposibilita la replicabilidad de resultados y deriva en publicaciones de ámbito nacional con poco impacto científico. En esta línea, Chi (2014) señala que el idioma se ha convertido en otra barrera de investigación en esta área puesto que, en países no anglosajones, los artículos de orientación nacional generalmente se publican en idiomas distintos del inglés, los cuales no tienen cabida en el 95% de las revistas incluidas en el SSCI.

Otra de las particularidades que recoge la investigación en Ciencias Sociales es la frecuente publicación en volúmenes editados y monografías. Nederhof (2006) insiste en que esto influye en la calidad y cantidad de las citas recibidas puesto que, a pesar de que los libros y capítulos de libro son más citados, tienden a tardar más en alcanzar sus picos de citas que los artículos de revistas. Por otro lado, las Ciencias Sociales también se caracterizan por un ritmo más pausado en su desarrollo y esto también puede reflejarse en las prácticas de citación, como el consumo y uso de literatura más antigua, o en la evolución e indexación de las revistas científicas (Mali, 2013; Nederhof, 2006). Harzing et al. (2014) señala que, además, en la investigación en Ciencias Sociales existe una tendencia a la publicación individual o en pequeños grupos que restringe la producción de autores y autoras. Asimismo, estos estudios sostienen que las demoras en la publicación o los mayores índices de rechazo de las revistas científicas de Ciencias Sociales frente a otras áreas contribuyen a un sesgo que limita la publicación y el crecimiento académico de los y las investigadores/as, especialmente durante el doctorado.

Ante estas barreras, Reale et al. (2018) o De Rijcke (2016) concluyen que la evaluación de la publicación científica en Ciencias Sociales no puede realizarse únicamente mediante la aplicación de indicadores bibliométricos, sino que es necesaria la búsqueda de alternativas que permitan una evaluación adecuada y no sesgada de la producción científica en este ámbito. Para ello, Sivertsen y Larsen (2012) proponen la creación de una base de datos bibliométrica robusta para medir el impacto de todo tipo de resultados de la investigación en Ciencias Sociales.

3.1.3. La Tesis por Compendio de Publicaciones

Autores como Alexander y Davis (2019) destacan que la educación doctoral es esencial para la producción y transferencia de conocimiento. En los últimos años, la tesis doctoral ha ido transformándose y creando nuevas formas de producción frente a la tesis tradicional, como son las tesis por compendio de publicaciones o las tesis por proyectos (Aitchison et al., 2010). Estas nuevas modalidades son comunes en disciplinas relacionadas con las ciencias y la tecnología, y poco visibles en humanidades y Ciencias Sociales (Niven & Grant, 2012).

Según Robins y Kanowski (2008), un doctorado tradicional es un proyecto de investigación supervisado que se realiza sobre la base de una tesis, mientras que un doctorado por compendio de publicaciones se basa en un proyecto de investigación supervisada, pero sobre la base de un serie de trabajos académicos revisados por pares que han sido publicados o aceptados para su publicación. Jackson (2013) señala que las tesis doctorales por compendio de publicaciones tienen un nivel similar que las tesis tradicionales y ambas confirman la competencia del doctorando para realizar una investigación con autonomía. No obstante, algunos autores como O'Keeffe (2020) sugieren que la realización de una tesis doctoral por compendio de publicaciones tiene ventajas respecto a las tesis tradicionales, las cuales pueden no pasar por un proceso anónimo y riguroso de revisión por pares. Entre estas ventajas, Robins y Kanowski (2008), destacan la eficiencia, puntualidad y retroalimentación, el fomento de prácticas profesionales acordes al desarrollo académico, y posicionan la publicación de la tesis doctoral como predictor de la productividad académica posterior.

En esta línea, Asongu y Nwachukwu (2018) señalan que esta modalidad de tesis, utilizada mayoritariamente en Reino Unido y, más concretamente, en áreas como la ingeniería, ofrece una oportunidad para la transferencia inmediata del conocimiento, así como una mayor producción científica del estudiantado predoctoral. Invita a que los investigadores e investigadoras juniors fomenten y demuestren sus capacidades de publicación antes de obtener el grado de doctor, al mismo tiempo que consolidan su identidad en la academia. Asimismo, el aprendizaje en el proceso de redacción y publicación de artículos permite a los candidatos y candidatas adquirir experiencia en la escritura colaborativa y el trabajo en equipos de investigación multidisciplinares que conllevan un alto grado de colaboración y coordinación (Peacock, 2017). Además, los duros procesos de revisión por pares de los artículos permiten al estudiantado tener más confianza en su trabajo, beneficiando así su lectura final. Esta modalidad es, por tanto, beneficiosa no sólo para la carrera académica del doctorando/a, sino también para el currículum académico sus directores/as, así como para la producción científica de la propia universidad (Courtney et al., 2005).

A pesar de las ventajas avaladas por la literatura, la tesis por compendio de publicaciones también se enfrenta a numerosos retos tanto para las personas candidatas como para sus supervisores/as. Los resultados de Asante y Abubakari (2020) o Pretorius (2017) concluyen que la ardua selección de la revista, los prolongados y laboriosos procesos de presentación, revisión y publicación, las diferentes pautas de autor de cada revista, la adaptación del estilo y la voz en la redacción de los artículos o la divulgación restringida, son factores que plantean un desafío para lograr una estructura clara y coherente de la tesis doctoral. Para paliar dichas incertidumbres, Merga (2015) recomienda instar a los doctorandos y doctorandas a escribir y enviar artículos para su revisión al inicio y de forma continuada durante todo el proceso de su candidatura para asegurar un margen de tiempo que permita garantizar la publicación de los artículos necesarios para la entrega de la tesis doctoral.

La supervisión en esta modalidad también adquiere un papel laborioso, aunque primordial. Tradicionalmente, las tutorías o reuniones de supervisión cubren temáticas habituales con el desarrollo del trabajo de investigación, tales como los objetivos del proyecto, metodología o la recopilación y el análisis de datos. Sin embargo, el estudio cualitativo realizado por Dowling et al. (2012) sobre experiencias del doctorado por publicación, concluyó que, en esta modalidad, la supervisión adquiere mayor importancia en la planificación y escritura, no sólo fomentando la realización y finalización de artículos, sino también revisando borradores y nuevas versiones y preparando al doctorando para interpretar y responder correctamente los comentarios de los revisores y revisoras.

3.2. Estudio Actual

Una preocupación clave de las políticas de investigación actuales es evaluar el impacto de la investigación, o el valor que genera la inversión en investigación, especialmente en el área de Ciencias Sociales. Siguiendo las recomendaciones de la literatura científica mencionadas en los apartados anteriores, la presente tesis doctoral se realiza a través del compendio de publicaciones. Se presentan cuatro artículos científicos publicados en revistas científicas de impacto internacional. Cada uno de los manuscritos corresponde a una fase y un objetivo de la investigación. El orden escogido para la presentación de las publicaciones corresponde a una exposición tanto cronológica como temática, regida por las diferentes metodologías utilizadas para la realización del estudio.

Esta tesis se ajusta a los requisitos para la presentación de tesis por compendio de publicaciones establecidos en el Reglamento sobre Depósito, Evaluación y Defensa de la Tesis Doctoral de la Escuela de Doctorado de la Universitat de València. Esta normativa exige la presentación de, al menos, tres artículos publicados o aceptados para su publicación en revistas indexadas en algún índice internacional como JCR y/o SJR en el caso de Ciencias Sociales. Asimismo, también cumple la normativa específica del

Programa de Doctorado en Ciencias Sociales que establece como criterios de calidad que deben reunir los artículos, la publicación de mínimo tres artículos indexados en JCR o SCOPUS. Para esta para esta última base de datos, por lo menos un artículo debe estar publicado en revistas indexadas en los primeros tres cuartiles. En la Tabla 2 se muestran las referencias de los artículos que constituyen el corpus de la presente tesis doctoral, así como sus principales características, las cuales serán descritas en los apartados siguientes.

Tabla 2

Publicaciones que configuran la tesis doctoral

	Publicaciones	**Detalles**
E1	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. https://doi.org/10.1590/s1980-220x2017029403351	Idioma: inglés y español Indexación: SJR (Q2) y JCR (Q4)
E2	Carbonell, A., Navarro-Pérez, J. J., & Mestre, M. V. (2019). Risk factors associated with the family care of people with serious mental illness. *Medicina Oral, Patología Oral y Cirugía Bucal*, *24*(4), 438-443. https://doi.org/10.4317/medoral.23133	Idioma: inglés Indexación: SJR (Q2) y JCR (Q3)
E3	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*, *17*(6), 743-760. https://doi.org/10.1080/15332985.2019.1668904	Idioma: inglés Indexación: SJR (Q2)
E4	Carbonell, A., Navarro-Pérez, J. J., & Mestre, M. V. (2020). Challenges and barriers in mental healthcare systems and their impact on the family: A systematic integrative review. *Health and Social Care in the Community*, *28*(3), 1-14. https://doi.org/10.1111/hsc.12968	Idioma: inglés Indexación: SJR (Q1) y JCR (Q1)

3.2.1. Metodologías de Investigación

Como señala Heesen et al. (2019), combinar diferentes perspectivas metodológicas permite mayor comprensión de una problemática y mejora la validez de la investigación. Aunque generalmente, la triangulación metodológica hace referencia a la combinación de datos cuantitativos y cualitativos (Bekhet & Zauszniewski, 2012), Lodhi (2016) defiende que estos métodos pueden beneficiarse de las revisiones de la literatura, las cuales muestran una visión general, completa y crítica de estudios relevantes pertenecientes a una temática concreta. Este estudio no busca la convergencia en el sentido clásico de triangulación, sino más bien una “expansión de la investigación" que implica un análisis secundario de los resultados obtenidos.

Para el desarrollo de la presente tesis doctoral, se utilizó un diseño de métodos mixtos y se realizaron secuencialmente tres procesos de investigación, combinando metodologías cuantitativas y cualitativas. De este modo, y siguiendo a Sánchez (2015), la vinculación de resultados centrados en diferentes aspectos del problema, pero que son complementarios entre sí, permite que las conclusiones generadas en las diferentes fases de la investigación puedan fortalecerse. La Tabla 3 muestra las características del diseño metodológico empleado para el estudio.

Tabla 3

Fases y diseño metodológico del estudio

Fase	Objetivo general	Técnica	Objeto	Objetivo específico	Artículo
Cuantitativa	Explorar los factores asociados a la sobrecarga de las cuidadoras familiares de personas con trastorno mental	Encuesta *107 cuidadores/as*	Nivel de sobrecarga familiar y variables sociodemográficas y clínicas de la cuidadora y persona cuidada	OE 1. Analizar las variables sociodemográficas y clínicas de las cuidadoras y de las personas cuidadas OE 2. Identificar la relación entre las variables sociodemográficas y clínicas que definen a la cuidadora y la sobrecarga OE 3. Establecer las variables que predicen la sobrecarga en cuidadoras familiares de personas con trastorno mental.	**E1**
		Encuesta *417 cuidadores/as*			**E2**
Cualitativa	Conocer la percepción de los profesionales de la salud mental sobre el cuidado familiar y la gestión de las políticas públicas en este ámbito	Grupo de discusión *8 profesionales del Trabajo Social*	Patrón guion para entrevistas	OE 4. Identificar las variables de estudio para conocer el alcance de la responsabilidad del cuidado familiar en salud mental	**E3**
		Entrevistas a profesionales *22 profesionales de salud mental*	Percepción de profesionales	OE 5. Explorar las barreras estructurales del modelo de salud mental desde una perspectiva psicosocial profesional.	
		Grupo de expertos *7 profesionales que ocupaban cargos directivos*	Validación de las categorías de las entrevistas		
Cualitativa	Analizar los desafíos y barreras de los sistemas de atención a la salud mental y su impacto en la familia	Revisión sistemática *32 artículos que cumplieron los criterios de inclusión*		OE 6. Sintetizar la literatura científica sobre las políticas públicas de atención a la salud mental y su impacto en la familia OE 7. Estudiar las características y la eficacia de las políticas de atención a la salud mental y su impacto en el bienestar y calidad de vida de las personas con trastorno mental y sus familiares.	**E4**

Fase 1. Estudios cuantitativos

En primer lugar, se llevó a cabo un estudio cuantitativo con el objetivo de explorar los niveles de sobrecarga de las personas que cuidan a otras con trastorno mental. Participaron cuidadoras de personas con trastorno mental grave atendidas en dispositivos sanitarios de atención a la salud mental de la provincia de Valencia y asociaciones de familiares y usuarios/as. Todas las cuidadoras participantes cumplieron una serie de criterios de inclusión. Como instrumento principal, se utilizó el Zarit Burden Inventory diseñado por Zarit y Zarit (1987), adaptado al español por Martin et al. (1996) que permite evaluar el grado de sobrecarga de las cuidadoras. Asimismo, se incluyeron variables sociodemográficas relativas a las cuidadoras y a las personas cuidadas. Se realizaron análisis descriptivos, pruebas de comparación de medias y análisis de correlaciones para analizar los datos.

Este proceso se realizó en dos momentos diferentes. En primer lugar, participaron un total de 107 cuidadoras. Para garantizar la representatividad de la muestra y la replicabilidad de resultados, posteriormente, se realizó otro estudio más amplio donde participaron 417 familiares que cuidan personas con trastorno mental grave. Ambos estudios fueron publicados tras tres rondas de evaluación en la Revista da Escola de Enfermagem da USP y Medicina Oral, Patología Oral y Cirugía Bucal respectivamente, atravesando un riguroso proceso de revisión por pares en el que intervinieron dos expertos o expertas.

Fase 2. Diseño de triangulación metodológica cualitativa

En función de los resultados obtenidos en la primera fase, en segundo lugar y con el objetivo de conocer la percepción de los profesionales de la salud mental sobre el cuidado familiar y la gestión de las políticas públicas en este ámbito, se llevó a cabo un proceso empírico que involucró tres procedimientos cualitativos en los que participaron 37 expertos y expertas de diferentes regiones de España. Con el fin de garantizar el rigor metodológico en la investigación cualitativa, se creó un grupo de discusión de profesionales del Trabajo Social para crear un guion de entrevista. Posteriormente, se realizaron entrevistas a 22 profesionales que atienden a personas con trastorno mental en diversos establecimientos públicos de todo el país. Un segundo grupo focal formado por siete profesionales que ocupaban cargos de gestión y dirección en servicios sociosanitarios de salud mental validó las categorizaciones analizadas en las entrevistas.

Esta triangulación de técnicas intramétodo permitió combinar diferentes métodos y técnicas de recolección de datos para acercarse al objeto de estudio, logrando una mayor precisión que si se hubiera aplicado una sola técnica (Denzin, 1978). Para la obtención de datos se realizó un análisis de contenido deductivo. Los datos se transcribieron y se llevó a cabo un proceso de categorización abierta. El procedimiento se adhirió de manera rigurosa a los estándares de objetividad para las investigaciones cualitativas, utilizando los criterios consolidados para informar la investigación cualitativa de la herramienta COREQ[5] (Tong et al., 2007). Tras tres rondas de revisión por pares en la que participaron dos evaluadores o evaluadoras, el estudio fue publicado en la revista Social Work in Mental Health.

Fase 3. La Revisión Sistemática

El tercer proceso de investigación derivó de los resultados de las investigaciones anteriormente mencionadas, así como de la necesidad de la literatura de analizar los desafíos y barreras de los sistemas de salud mental y el impacto que tienen en la familia (Wykes et al., 2015). Para ello, se llevó a cabo una revisión integradora sistemática que permite analizar métodos de investigación heterogéneos proporcionando una comprensión más amplia de la temática (Whittemore & Knafl, 2005). Las búsquedas se realizaron en las bases de datos Web of Science, Scopus, Medline y Cochrane, utilizando términos relacionados con la salud mental, la atención familiar y los sistemas de salud.

Este proceso identificó 32 artículos que cumplieron con los criterios de inclusión e indicadores de calidad, siguiendo la guía para la realización y publicación de revisiones sistemáticas PRISMA-P[6] (Moher et al., 2015). La síntesis narrativa de las fuentes se desarrolló mediante un análisis de contenido inductivo (Finfgeld-Connett, 2014), analizando los hallazgos de los estudios incluidos y describiendo las principales categorías y subcategorías emergentes de los datos recolectados. Los resultados de este estudio fueron publicados en la revista Health and Social Care in the Community siguiendo un riguroso proceso de tres rondas de evaluación en el que participaron tres revisores o revisoras expertos.

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[5] Ver ANEXO 7.3. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist.

[6] Ver ANEXO 7.4. PRISMA-P 2015 Checklist: Recommended Items to Include in a Systematic Review Protocol.

3.2.2. Contribuciones y Autoría de las Publicaciones

En la actualidad, la autoría en las publicaciones científicas no sólo tiene una gran relevancia académica, sino también financiera y social. Realizar, publicar y difundir resultados confiere una responsabilidad y un reconocimiento científico que puede materializarse de diferentes formas (Ilarraza-Lomelí & García-Saldivia, 2015). En las tesis por compendio de publicaciones, generalmente los artículos están realizados en coautoría con los supervisores o supervisoras (Paré, 2017). Un estudio desarrollado por Li et al. (2019) para examinar el impacto de la autoría en la carrera académica de jóvenes investigadores/as determinó que la coautoría temprana con científicos/as de renombre predice el éxito en las carreras académicas.

En esta tesis doctoral, siguiendo a Fees (2014), director, directora y doctoranda, en mayor o menor rango, aportaron contribuciones sustanciales durante el diseño del estudio, análisis o interpretación de los datos, redactaron o revisaron el documento de manera crítica, aprobaron la versión final, y garantizaron que el trabajo fue realizado de manera precisa y con integridad. La doctoranda asumió con mayor grado de compromiso, participación y autoría en tres de los cuatro artículos publicados. La supervisión y el apoyo institucional fueron cruciales para el diseño, acceso, análisis y recolección de los datos, así como para la redacción de los manuscritos y el afrontamiento de la revisión por pares.

La lista de autoría fue ordenada jerárquicamente (Ver Tabla 4) según el sistema de puntuación diseñado por Petroianu (2002)[7], el cual evalúa la participación de cada uno en el estudio científico. Este sistema establece una puntuación única para cada ítem, según la carga de trabajo. Los colaboradores y colaboradoras que hayan obtenido un mínimo de siete puntos tendrán derecho a la autoría y la secuencia de los autores y autoras debe realizarse orden decreciente de puntuación.

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[7] Ver ANEXO 7.5. Pontuação para Autoria, de acordo com a Participação no Trabalho

Tabla 4

Puntuación de la autoría según la participación en el trabajo

	Estudio 1			Estudio 2			Estudio 3			Estudio 4		
Participación	**A1**	**A2**	**A3**	**A1**	**A2**	**A3**	**A1**	**A2**	**A3**	**A1**	**A2**	**A3**
Crear la idea que originó el trabajo y desarrollar hipótesis/objetivos	6			6			6			6		
Estructurar el método de trabajo		6		6				6		6		
Guiar o coordinar el trabajo		5			5			5			5	
Redactar el manuscrito	5	5		5			5	5		5		
Coordinar el grupo que realizó el trabajo		4			4			4			4	
Revisar la literatura	4	4		4			4			4	4	4
Presentar sugerencias relevantes integradas en el trabajo		4			4	4		4	4	4	4	4
Resolver problemas laborales fundamentales		4										
Diseñar los instrumentos de recogida de datos	3			3			3			3		
Recolectar datos	3			3			3			3		
Analizar los resultados	3			3			3	3	3	3	3	3
Guiar la redacción del manuscrito		3			3		3			3		
Preparar la presentación del trabajo para evento científico	3			3			3			3		
Presentar el trabajo en un evento científico	2			2			2			2		
Dirigir el lugar donde se realizó el trabajo												
Proporcionar la muestra para el trabajo	2					2		2				
Recaudar financiación		1			1	1		1	1		1	
Presentar sugerencias menores integradas en el trabajo	1					1				1	1	1
Trabajar en la rutina del trabajo, sin aporte intelectual												
Participar por pago específico												
Puntuación total	32	36	—	35	17	8	32	30	8	43	22	12

*A1 = Ángela Carbonell; A2 = José-Javier Navarro-Pérez; A3 = María-Vicenta Mestre

** Fuente: Elaboración propia a partir de Petroianu (2002).

3.2.3. Índices de Impacto y Calidad de las Publicaciones Presentadas

Revista da Escola de Enfermagem da USP

El artículo original de investigación, titulado “Family burden, social support and community health in caregivers of people with serious mental disorder” está publicado en la Revista da Escola de Enfermagem da USP (REEUSP). Esta es una revista trimestral, creada en Brasil en el año 1967 por la Escola de Enfermagem de la Universidade de São Paulo con el objetivo de publicar artículos empíricos o teóricos que representen un avance significativo para la práctica profesional o para los fundamentos de enfermería y otras áreas afines. Todos los trabajos publicados en esta revista son originales y están sometidos al dictamen de, al menos, dos evaluadores/as. Esta revista se encuentra indexada a múltiples bases de datos internacionales que representan claros indicios de calidad y de la difusión internacional de la revista.

La revista está incluida en la WoS de Clarivate Analytics y cumple con una serie de criterios y requisitos de calidad muy exigentes requeridos para ser incluida en esta base de datos. La revista está indexada en las bases de datos SCIE y SCCI. Se adscribe a la categoría “Nursing”, con un factor de impacto de .798, posicionándose en el cuarto cuartil del Jounal Citation Reports en 2019.

Esta revista también se encuentra indexada en la base de datos internacional Scopus de Elsevier, competencia de ISI Web of Science, y de similares características. Esta revista no sólo está indexada en Scopus, sino que además cuenta con el indicador científico SJR, homologable al factor de impacto JCR (González-Pereira et al., 2010). REEUSP se posiciona actualmente en el segundo cuartil en la cateogría “Nursing (miscellaneous)” con un valor SJR de .314 en 2019.

La revista se encuentra como como una de las revistas brasileñas con mayor impacto medido en el índice *h* según Google Scholar Metrics. En 2020, la revista cuenta con un índice *h5* de 33 y Mediana *h5* de 41 según las citas de los artículos publicados en los últimos 5 años completos (2015-2019).

Según la Clasificación Integrada de Revistas Científicas (2020), REEUSP está clasificada como grupo B en la Clasificación de Ciencias Sociales. Según los editores y editoras del producto, el grupo de revistas clasificadas como B está formado por revistas científicas de calidad que reciben cierto grado de citación y que respetan los estándares de publicación, aunque con un grado medio de difusión internacional.

Asimismo, la revista se encuentra indexada en otras bases de datos internacionales de prestigio, como CINAHL, EMBASE, MEDLINE, Educational Research Abstracts (ERA). Puede encontrarse en bases de datos de prestigio como CUIDEN, REDALyC, Scielo y LILACS. La revista se puede consultar en varias plataformas múltiples de bases de datos, como EBSCOhost, Taylor & Francis, o Adis International, entre otras. En el catálogo Latindex la revista cumple con 30 de 33 criterios de calidad científica empleados para revistas científicas impresas, en DOAJ y en ULRICHS, y con 36 de los 38 criterios de calidad científica empleados para revistas científicas online.

Según los sistemas de evaluación de revistas regionales para medir la calidad de las revistas donde publican los investigadores e investigadoras, REEUSP está incluida en CONICET (Consejo Nacional de Investigaciones Científicas y Técnicas) como Grupo 1 según Res. 2249/14, en Qualis-CAPES A2 (sistema de evaluación brasileño adoptado por la Coordenação de Aperfeiçoamento de Pessoal de Nível Superior), Periódica (Índice de Revistas Latinoamericanas en Ciencias), e Iresie (Índice de Revistas de Educación Superior e Investigación Educativa).

Medicina Oral, Patología Oral y Cirugía Bucal

El artículo titulado “Risk factors associated with the family care of people with serious mental illness” está publicado en la revista Medicina Oral, Patología Oral y Cirugía Bucal. Esta es una revista de investigación científica bimestral, publicada en inglés, que incluye trabajos sobre aspectos clínico-patológicos, terapéuticos médicos y/o quirúrgicos de las enfermedades relacionadas con la cavidad oral y la odontología. Además, esta revista también publica artículos de temática abierta relacionada con cualquier área de la salud, especialmente problemáticas de estrés y ansiedad, para dar mayor visibilidad a la transversalidad de la revista.

Según Valderrama et al. (2020), actualmente, esta revista es la publicación oficial de una sociedad profesional iberoamericana y seis españolas: la Sociedad Española de Medicina Oral de España, la Academia Iberoamericana de Patología y Medicina Bucal, la Sociedad Española de Odontología para el Minusválido y Pacientes Especiales, la

Sociedad Española de Cirugía Bucal, la Sociedad Española de Gerodontología, la Sociedad Española de Láser Odontoestomatológico, y la Sociedad Española de Disfunción Craneomandibular y Dolor Orofacial.

La revista está indexada en diferentes bases de datos de gran prestigio nacional e internacional, como la WoS, Scopus, SCIE, Index Medicus, MEDLINE, PubMed, EMBASE y EMCARE. Desde su inicio en 2004, la revista fue incluida en Dialnet. En 2009, la revista fue evaluada e incluida en Latindex y, en la actualidad, cumple con 32 características del catálogo. Además, también se encuentra incluida en el Índice Médico Español (IME), una base de datos bibliográfica que contiene la producción científica publicada en España en Biomedicina desde los años 70. La revista puede consultarse en plataformas como EBSCOhost, Scielo, NCBI o Europe PMC, entre otras.

Cuenta con un factor de impacto de 1.596 del Journal Citation Reports en 2019, posicionándose dentro del tercer cuartil. Actualmente es la única revista española incluida en JCR en la categoría “Dentistry, Oral Surgery & Medicine”. Además, se sitúa actualmente en el segundo cuartil de las categorías “Medicine (miscellaneous)”, “Dentristy (miscellaneous)”, “Otorhinolaryngology”, y “Surgery”*,* con un valor SJR de .62 en 2019. Según Google Scholar Metrics, la revista cuenta con un índice *h5* de 31 y Mediana *h5* de 41. Actualmente es la única revista española de estas categorías que ha sido indexada en los índices y repertorios internacionales de mayor prestigio.

Social Work in Mental Health

El artículo de investigación titulado “The care crisis in Spain: an analysis of the family care situation in mental health from a professional psychosocial perspective” está publicado en la revista Social Work in Mental Health (SWMH). Esta es la revista con mayor tradición entre los y las profesionales del Trabajo Social de todos los sectores de la atención de la salud mental de Estados Unidos. Ofrece artículos, artículos de revisión o reseñas de libros de calidad relacionados con la práctica clínica, educación, investigación, relaciones de colaboración, políticas de salud mental y la prestación de servicios de atención de salud mental. Está dedicado a la teoría, práctica y administración del Trabajo Social en una amplia variedad de entornos de atención de salud mental. Todos los artículos de investigación publicados en esta revista han sido sometidos a una rigurosa revisión por pares, basada en la selección inicial del editor y la evaluación anónima de mínimo dos árbitros.

Esta revista es editada por Taylor & Francis y está indexada en las bases de datos British Library Inside, Cambridge Scientific Abstracts, CINAHL, y CSA Social Services Abstracts. SWMH puede consultarse en plataformas como EBSCOhost, Elsevier Scopus, International Bibliography of Periodical Literature on the Humanities and Social Sciences, PsycINFO, PSYCLINE, Social Work Abstracts, y SocINDEX. Además, la revista es filial de la revista Social Work in Health Care, incluida en SCIE y el Journal Citation Reports.

La revista está indexada en la base de datos Scopus y, utilizando los cuartiles y factores de impacto de Scimago Journal y Country Rank, cuenta con un índice de impacto de .39 en 2019. Se adscribe a las categorías de “Social Sciences”, “Social Work” y “Public Health, Environmental and Occupational Health” en el segundo y tercer cuartil. La revista cuenta con un índice *h5* de 15 y una mediana *h5* de 18, según Google Scholar Metrics. SWMH está clasificada como grupo B, según la clasificación CIRC en 2020.

Health and Social Care in the Community.

El artículo titulado “Challenges and barriers in mental healthcare systems and their impact on the family: A systematic integrative review” está publicado en 2020 en la revista Health and Social Care in the Community (HSCC). Esta es una revista internacional revisada por pares dirigida a profesionales del trabajo social o cualquier otra área de la salud con enfoque comunitario o de salud pública, como profesionales de la salud pública, medicina de familia, enfermería comunitaria e investigadores/as y docentes de atención social. La revista promueve el pensamiento crítico y el debate informado sobre todos los aspectos de la salud y la atención social. Esta revista publica revisiones sistemáticas y narrativas, análisis de políticas, documentos empíricos cualitativos o cuantitativos, y documentos que se centran en la educación profesional o del usuario. Estas deben ser investigaciones originales que muestren la amplia gama de políticas, prácticas y cuestiones teóricas que sustentan la prestación de atención en la comunidad.

En la actualidad, esta es la quinta revista de trabajo social con mayor impacto del mundo. HSCC está indexada en múltiples bases de datos de gran prestigio, tales como SCCI, CINAHL, AMED, CABI, MEDLINE y PubMed, entre otras. Se posiciona en el primer y segundo cuartil de las categorías “Social Work” y “Public, Environmental and Occupational Health”, respectivamente, del Jounal Citation Reports en 2019. La revista está indexada en Scopus y Elsevier y cuenta con el indicador científico SCImago Journal

Rank (SJR) con un valor de .805 en 2019. Está adscrito a las categorías “Social Work”, “Sociology and Political Science”, y “Social Sciences (miscellaneous)” en Q1, y a las categorías “Public Health, Environmental and Occupational Health” y “Health Policy” en Q2.

HSCC cuenta con un índice *h5* de 35 y una mediana *h5* de 46, según Google Scholar Metrics. Según la clasificación CIRC, en 2020, la revista está clasificada como grupo A+ en Ciencias Sociales, lo que significa que, además de formar parte de un reducido grupo de revistas de excelencia que cuentan con un gran impacto y prestigio internacional, se caracteriza por su alto impacto en todas sus categorías, lo que la sitúa como revista referente en todas sus disciplinas. Asimismo, la revista se puede consultar en varias plataformas múltiples de bases de datos como PsycINFO, ProQuest, British Library o NLM, entre otras.

CAPÍTULO 4. ARTÍCULOS PUBLICADOS EN REVISTAS DE ALTO IMPACTO CIENTÍFICO

ESTUDIO 1. Family burden, social support, and community health in caregivers of people with serious mental disorder

REFERENCIA

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. https://doi.org/10.1590/s1980-220x2017029403351

* Este apartado contiene el texto de la versión del artículo aceptada por la revista. Para que la presente tesis doctoral sea coherente, la versión final ha sido adaptada en lo que respecta a la numeración de figuras, tablas y epígrafes. Se ha adaptado la normativa de citación y el diseño del documento a las Normas APA 7th Edición. La versión final publicada puede consultarse en la fuente original de publicación y en los documentos anexados al final de esta tesis doctoral.

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Family burden, social support and community health in caregivers of people with serious mental disorder*

Sobrecarga familiar, apoyo social y salud comunitaria en cuidadores de personas con trastorno mental grave

Sobrecarga familiar, apoio social e saúde comunitária em cuidadores de pessoas com transtorno mental grave

José Javier Navarro Pérez[1], Ángela Carbonell Marqués[1]

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ABSTRACT

Objective: To identify caregivers' level of burden and analyze the factors associated with family care in mental health. **Method:** A cross-sectional descriptive study was conducted between January and July 2016. A sample of caregivers from seven public institutions and an association of relatives and patients was evaluated by identifying their burden and the contributing factors for reduction of these levels through the Zarit Burden Inventory instrument. The study was conducted according to recommendations of the ethics committees of the participating institutions. **Results:** Participation of 107 caregivers. The main contributions refer that caregivers' active participation in associative dynamics, their attendance at psychoeducational activities and territorial connection to metropolitan areas with community resources decrease their level of burden. **Conclusion:** Community nursing is highly important and responsible for preventing levels of burden and increasing health levels. In addition, many proposals are formulated in order to favor social support networks by combining treatments and increasing public health programs in contact with the community.

DESCRIPTORS

Mental Disorders; Caregivers; Family; Social Support; Community Health Nursing.

[*] Extracted from the thesis: "Factores asociados al cuidado familiar de una persona con Trastorno Mental Grave", Universidad de Valencia, 2016.

[1] Universidad de Valencia, Facultad de Ciencias Sociales, Departamento de Trabajo Social y Servicios Sociales, Valencia, Spain.

Corresponding author:
Ángela Carbonell Marqués
Facultad de Ciencias Sociales,
Universidad de Valencia
Avenida dels Tarongers, 4b, Despacho 1D19
46022 – Valencia, Spain
angela.carbonell@uv.es

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Family burden, social support, and community health in caregivers of people with Serious Mental Disorder

4.1.1. Abstract

Objective: To identify caregivers' level of burden and analyze the factors associated with family care in mental health.

Method: A cross-sectional descriptive study was conducted between January and July 2016. A sample of caregivers from seven public institutions and an association of relatives and patients was evaluated by identifying their burden and the contributing factors for reduction of these levels through the Zarit Burden Inventory instrument. The study was conducted according to recommendations of the ethics committees of the participating institutions.

Results: Participation of 107 caregivers. The main contributions refer that caregivers' active participation in associative dynamics, their attendance at psychoeducational activities and territorial connection to metropolitan areas with community resources decrease their level of burden.

Conclusion: Community nursing is highly important and responsible for preventing levels of burden and increasing health levels. In addition, many proposals are formulated in order to favor social support networks by combining treatments and increasing public health programs in contact with the community.

Descriptors: Mental Disorders; Caregivers; Family; Social Support; Community Health Nursing.

4.1.2. Introduction

Serious mental disorders (SMD) involve several psychiatric diagnoses of prolonged duration, which result in a high degree of physical, mental and social disability that reduces the quality of life of affected individuals and their family (Mata et al., 2016).

De León et al. (2016) describe this type of illness as one of the predictors of risk of dependency, because it causes significant loss of autonomy and demands constant attention and assistance from another person for performing basic and instrumental activities of daily life. In many cases, this is the reason for the constant need for attention and support required by this group of people, since the illness causes disability. Together with the lack of resources, that fact means the care of people with a serious mental disorder falls fundamentally in the hands of relatives, who place themselves as caregivers and responsible for the well-being of family members (Bellato et al., 2016). In general, this care becomes responsibility of a single member of the family who, almost exclusively, is a woman.

Family caregivers' main function is helping to meet the dependent person's basic and instrumental needs of daily life (Silva et al., 2016). The main caregivers are exposed to various challenges and stressors on a daily basis, which make them feel loss of personal control, and result in physical and emotional alterations that can lead to the 'Caregiver syndrome' (Echevarría et al., 2014), and confrontation of a wide variety of risk factors that undermine their well-being. In addition, this pathology integrates a series of negative personal and work factors affecting informal caregivers' well-being, and giving rise to feelings of emotional exhaustion, depersonalization and even lack of personal fulfillment outside family care. This can be motivated by the loss of work and job opportunities experienced by people devoting most of their time to the care of a family member, which worsens the economic situation because of direct costs and decreased family productivity (Parekh et al., 2017). The consequences of caregivers' great investment of time are less leisure and social relations, the projection of frailties around them, and vulnerability in situations of isolation and social exclusion (Ribé et al., 2017).

The care of people diagnosed with a serious mental disorder presupposes significant economic, mental and personal exhaustion of those responsible for their daily care (Ong et al., 2016). The scientific literature emphasizes that caring for people with serious mental disorders is a heavier burden than caring for people with other types of diseases (Thunyadee et al., 2015). Some factors influencing this deterioration are the burden of caring for a sick person, lack of specific training for the provision of adequate care, and the preparation to face the intrinsic situations to that same care (Guerra & Zambrano, 2013). All these aspects together with the stigma and social rejection of the illness itself and its association with violence, support the false social belief that people suffering from SMD are aggressive because of the disease nature hence this is considered a risk factor for the care. This issue is enhanced by the way it affects interpersonal relationships, the lack of balance between the illness cost and the belief that violent behaviors arise as a demonstration of disappointment, stigma and rejection towards the disorder itself (Fasihi et al., 2017).

Different authors have tried to evaluate the impact of sociodemographic and clinical variables both of people with serious mental disorders and their caregivers, and of the burden. The results of these studies associate a higher level of burden based on variables such as sex, kinship, having a paid job, the type of mental disorder, etc. On the other hand, these authors correlate positively the caregiver's age, years of disease evolution, number of hospital admissions and the degree of disability and dependency as variables associated with the main caregiver's burden (Geriani et al., 2015; Zhou et al., 2016). Likewise, social support is a protective factor to face care situations because it positively affects caregivers' psychological well-being and quality of life. According to these studies, caregivers experience greater burden when the perceived social support is lower (Barrera-Ortiz et al., 2016; Mao & Zhao, 2012; Kate et al., 2013).

The models of care for dependent individuals have changed over time in order to adapt to the needs and respond to this group's psychic and psychosocial problems. In Spain, the social care model for dependent individuals has favored their maintenance in the family and social context, which makes families the main support and care axis. Nursing is an area responsible for providing health education and care in the best possible conditions, not only to sick people, but also to their caregivers by assessing the possible effects of this work on them (De Jacq et al., 2016). In this sense, community nursing is key in the process of psychophysical rehabilitation, support and social integration of people with illnesses and their caregivers (Wright & Stickley, 2018).

Thus, the need to investigate the situation of people who dedicate their lives to the care of another person (Espinoza & Jofre, 2017; Masana, 2017). Therefore, the objective of the present study has two aspects; on the one hand, to identify caregivers' level of burden, and on the other, to analyze the factors associated with family care in mental health.

4.1.3. Methods

Type of Study

A cross-sectional descriptive study was performed by using the survey data collection technique. The study period was between the months of January and July 2016 in seven mental health care institutions in the province of Valencia and in an association of relatives and patients.

Participants

The sample included 107 caregivers who met the following inclusion criteria: caregivers of people with SMD included in the public system of Mental Health care in the Valencian Community; residence in the province of Valencia; presence of kinship ties with the sick person; age over 18 years old; performance of the primary caregiver role by adopting functions of care and supervision in basic and/or instrumental activities of daily life of the person with mental health problems; absence of remuneration for the work they do; performance of care for more than six months.

Exclusion criteria were to reject participation in the study, caregivers of people with diagnoses not classified as serious mental disorders (intellectual disability, behavioral or psychomotor development alterations) or for not being correctly completed.

Instruments

The Zarit Burden Inventory/Zarit Test (Martin et al., 1996; Zarit & Zarit, 1983) was chosen as the data collection instrument given the extensive scientific literature demonstrating the use and validity study of this scale (Kahn et al., 2016). The aim of this instrument is the assessment of the level of burden experienced by caregivers of people with dementia. However, it has also been used for caregivers of people with mental illness because of the similar chronicity of both groups (Rofail et al., 2016; Vella & Pai, 2012). In the present study, was obtained a Cronbach's alpha coefficient of 0.92 for the scale.

In order to analyze the sociodemographic characteristics of caregivers and identify their relationship with the level of burden, were collected the most present sociodemographic and clinical variables in the scientific literature and that according to authors, are related to the Caregiver syndrome, namely: 1) Variables describing the caregiver: age, sex, marital status, kinship with the sick person, having paid work, presence of chronic illness, active associationism, attendance at family psychoeducational talks and workshops, geographical environment and type of care received; and 2) Variables describing the person with SMD: age, sex, diagnosed illness, years of evolution of the disease, recognized degree of disability, and Mental Health care service they use.

Procedure

Considering the Spanish Mental Health care system does not attend caregivers directly, data collection was performed in seven institutions of the public Mental Health care system in the Valencian Community, province of Valencia, and in an association of relatives and patients. The community nurses used the appointments attended by users with a family member for identifying, from their professional judgment, those who performed the role of main caregiver of the person served (user).

An individualized interview was arranged with each study participant. Assessments were performed by community nurses with training in application of instruments. When a high level of burden was detected, the interviewee was informed about the existence of psychoeducational programs for relatives.

This study was conducted in accordance with recommendations of the ethics committees of participating institutions and met the national (Law 14/2007, of July 3 of biomedical research) and international standards of ethics in research. The results of the present study are taken from a broader study approved by the Commission of Ethics and Experimental Research of the Faculty of Social Sciences of the University of Valencia under reference number 000217/UV-Soc/2016. Subjects who met the inclusion criteria for this study received prior information and gave their written consent for voluntary participation according to the Declaration of Helsinki (2013). Participants were explained about the possibility of interrupting or withdrawing their participation at any time.

Data Analysis

For the quantitative analysis, firstly, was performed a descriptive study of data for identifying the characteristics of the caregiver and the person cared for based on sociodemographic and clinical variables. Then, was identified the relationship between the variables defining the caregiver and the person cared for, and the burden. Contingency tables and chi-square tests were used to verify statistically significant differences between the burden and nominal variables. A correlation analysis was performed in order to demonstrate the existence of a linear relationship between the level of burden and quantitative variables. Finally, was performed a linear regression with the variables that had a significant relationship with the level of burden in previous analyzes in order to define a predictive model of burden. Nominal variables were recoded as Dummy variables (fictitious) so they could be incorporated into the regression model. The data analysis process was performed with use of the IBM SPSS Statistics 25 software. For all tests, $p<0.5$ was considered as the level of statistical significance.

4.1.4. Results

Caregivers' Characteristics

The total sample of the study included 107 family caregivers of people with Serious Mental Disorder treated in seven public mental health care services and an association of relatives and patients (Table 5). Women represented 71% of the sample, and 29% were men, age was between 16 and 89 years old (M = 60.67, SD = 13.83). Regarding marital status, 51.4% were married, 15% were divorced, 21.5% were widowed and 12.1% were single. Among interviewees, 41.1% had a paid job, and the same percentage claimed to have a chronic disease. Most caregivers were fathers/mothers of the person with SMD (78.5%), 12.1% were siblings, 4.5% were children, 3.7% were spouses and 0.9% were uncles/aunts. Of caregivers participating in the study, 48.6% had previously assumed the care of another person. This same percentage had attended psychoeducational talks for relatives in Mental Health services and 15% participated in associative activities for relatives and people with SMD.

The subjects diagnosed with chronic mental disorders were mostly male (72.4%), aged 38.64 years (SD = 12.63) on average (ranging between 16 and 80 years). All were diagnosed with some Serious Mental Disorder, and the following stood out: schizophrenia (63.6%), bipolar disorder (15.9%), personality disorders (10.3%), dysthymia and chronic depression (4.7%). Obsessive compulsive disorder and schizophrenia, dual pathology and schizoaffective disorder appeared in lower percentages with 1.9% each. Of these people, 50.5% had a Recognition of the Degree of Disability of 65% or higher, while 19.6% did not have it recognized or had not requested it. The mean number of years of evolution of the disease was 17.28 (SD = 13.18) and ranged between three months and 56 years.

Table 5

Sociodemographic characteristics of the caregiver and the person cared for -Valencia, Spain, 2016

Caregivers' characteristics		**Characteristics of the person cared for**	
Age (years)	60.67±13.83	Age (years)	38.67±12.63
Sex (female)	71%	Sex (Male)	72%
Marital status			
Married	51.4%	Diagnosis	
Divorced	15.0%	Schizophrenia	63.6%
Widowed	21.5%	Bipolar disorder	15.9%
Single	12.1%	Depression	4.7%
Paid work (yes)	41.1%	OCD and Schizophrenia	1,9%
Chronic disease (yes)	41.1%	Personality disorder	10.3%
Relationship with the person		Dual pathology	1.9%
Spouse	3.7%	Schizoaffective disorder	1.9%
Brother/Sister	12.1%		
Father/Mother	78.5%	R. of Degree of Disability	
Son/Daughter	4.7%	Unrecognized	19.6%
Uncle/Aunt	0.9%	Less than 65%	29.9%
Active associationism (yes)	15%	65% or more	50.5%
Previous care of another family member (yes)	48.6%	Years of disease evolution	17.28±13.18
Psychoeducational (yes)	48.6%		

Caregivers' Burden

After applying the Zarit scale, scores demonstrated that 73.8% of interviewed people obtained severe level of burden, 9.3% mild burden and 16.4% did not show levels of burden.

Relationship between the level of burden and sociodemographic and clinical variables. The performance of chi-square tests resulted in factors in which there was no significant relationship of p <0.05 with the level of burden, such as the caregiver's sociodemographic variables of sex, age, kinship, marital status, prior care; as well as sex, age, diagnosis, recognition of the Degree of Disability and years of evolution of the person cared for. Significant relationships were found between the level of burden and variables of family intervention type (p=,000), associationism (p=,000), psychoeducational activities (p=,000), and geographical environment (p=,021). Thus, caregivers who received continuous care in a mental health care service, actively participated in some association, who had attended psychoeducational talks for relatives or who lived in metropolitan areas, had a lower level of burden than the rest of participants. In the Pearson correlation analysis, was found no relationship between quantitative variables and the caregiver's level of burden.

Linear regression model. When using variables that had a significant relationship with the caregiver's level of burden (type of care, associationism, psychoeducational and geographic environment), the linear regression analysis created two predictive models of burden (Tables 6-8):

The first model obtained significance p=.000, which explains non-attendance at psychoeducational talks as predictors of burden. Therefore, people who attended these activities had 19.4 less points of burden than those who never attended.

In the second model, active associationism and attendance at psychoeducational talks and activities were predictors of lower burden. Caregivers who had attended these programs (p=.00) had 15 less points of burden than those who never did. Likewise, caregivers who participated actively in an association (p=,001) had 14.4 less points of burden than those who never participated.

Table 6

Summary of the regression model of caregivers' burden in a sample of family caregivers - Valencia, Spain, 2016

Model	R	R squared	Adjusted R squared	Typical error of estimate
1	.558[a]	.312	.305	14.562
2	.619[b]	.383	.371	13.853

a. Predictors: (Constant), Psychoeducational
b. Predictors: (Constant), Psychoeducational, Associationism

Table 7

Summary of the ANOVA of caregivers' burden in a sample of family caregivers - Valencia, Spain, 2016

ANOVA[a]

Model		Sum of squares	Df	Half quadratic	F	Sig.
1	Regression	10076.766	1	10076.766	47.520	.000[b]
	Residue	22265.440	105	212.052		
	Total	32342.206	106			
2	Regression	12383.435	2	6191.717	32.263	.000[c]
	Residue	19958.771	104	191.911		
	Total	32342.206	106			

a. Dependent variable: Caregivers' burden
b. Predictors: (Constant), Psychoeducational
c. Predictors: (Constant), Psychoeducational, Associationism

Table 8

Regression coefficients of caregivers' burden in a sample of family caregivers - Valencia, Spain, 2016

Model		Unstandardized coefficients		Standardized coefficients	t	Sig.
		B	Typ. error	Beta	B	Typ. error
1	(Constant)	75.782	1.964		38.594	.000
	Psychoeducational	-19.416	2.817	-.558	-6.893	.000

2	(Constant)	75.782	1.868		40.569	.000
	Psychoeducational	-14.976	2.970	-.431	-5.043	.000
	Associationism	-14.431	4.162	-.296	-3.467	.001

a. Dependent variable: Caregivers’ burden

In accordance with the second model obtained in the linear regression, the burden of the caregiver of a person with Serious Mental Disorder would be represented by the following:

$$Y^1 = B_0 + B_1 X1 + B_2 X_2$$

BURDEN = 75,78 + (-14,976) Psychoeducational + (-14,431) Associationism

4.1.5. Discussion

Serious mental disorders cause effects on biological, psychological and social spheres of people affected by these illnesses, which makes them a susceptible population for receiving long-term care and assistance (De León et al., 2016; Mata et al., 2016). Studies refer that people who care for another with a serious mental disorder have high levels of burden, which leads to a series of psychological, physical, economic and social factors that negatively affect the caregiver (Ong et al., 2016). In the present study, were identified variables associated with the burden perception of family caregivers of people with serious mental disorders.

The predominant profile is that of a woman, average age of 60 years, married, usually the mother of the person with mental disorder and who does not have a paid job. The present study shows the high feminization as one of the main characteristics defining formal and informal care, since 71% of people performing the care were women, which is in line with authors (De León et al., 2016; Masana, 2017), and demonstrates how evident and necessary is an approach from the gender perspective in informal care.

The scientific literature defends the relationship between the sociodemographic variables of the caregiver and the person cared for and the illness characteristics with the level of burden and risk factors. The most prominent variables in the studies were the following: age, sex, professional occupation and educational level of the caregiver; as well as kinship, age, years of evolution of the illness and severity of symptoms of the person cared for (Geriani et al., 2015; Zhou et al., 2016). However, given the high levels of burden found in most subjects under study, the statistical tests performed for quantitative data analysis indicate that in this sample, the burden had no significant relationship with any of these variables, as it depends on the social support (formal and informal) received by the caregiver.

Different studies (Barrera-Ortiz et al., 2016; Mao & Zhao, 2012; Kate et al., 2013) emphasize the importance of social support as a variable that moderates the negative impact of performing the caregiver’s role, as a stress shock absorber. In the present study, professionals’ access to continuous care, active associationism and attendance at psychoeducational talks and workshops for relatives determined caregivers’ levels of burden. Likewise, and coinciding with those authors, these last two variables enabled the definition of a predictive model of burden in which people with higher social support showed lower levels of burden because of the care they perform.

In recent studies, was emphasized the high impact of the family as a channel of access to socialization (Guo et al., 2015). This dimension favors the coping of members of the family nucleus (Paul, 2015) by highlighting among these, the social support provided by parents and the potential generated from the network of relationships. Our results address this issue, as social support possibilities were built from the immersion of both relatives and patients in community activities. We agree with other analyzes (Whitley et al., 2016) that confirm the importance of a stable affectivity in everyday family relationships as a key factor for social adjustment and reduction of emotional burden.

Studies (Lambert et al., 2016) state that the lack of social support in stressful situations affects the stability of people in need of help and consequently, of those around them or with whom they live, and related the parents’ commitment to psychoeducational activities with lower levels of stress. These data are in line with our results, since relatives who attended support activities for the illness, felt less burden.

In parallel, metropolitan areas have greater and better possibilities of integration for people with SMD and their relatives given the wider and diversified offer. Our results were close to those of other authors, because in rural areas or those with less supply, the level of burden and even mortality was higher compared to large cities or those with greater prosocial leisure opportunities, diversified offer or recreational areas. The community is highly important for the collective development and welfare; therefore, the creation of social support networks improves the quality of life and mental health of its members (Silveira et al., 2016).

Nursing faces the challenge and opportunity of making care significant and a priority for mental health by ensuring continuity of care and formal support that can answer sensitively and effectively to the needs of subjects and their caregivers (De Jacq et al., 2016; Wright & Stickley, 2018).

4.1.6. Conclusion

Serious mental disorders are considered a public health problem worldwide that mainly affects the quality of life of people who suffer from it and their families. People with serious mental disorders sometimes require assistance and support for the performance of daily tasks. The person who assumes the caregiver role has several risk factors associated with the burden arising from this work. For this reason, informal caregivers are a group at risk, because they find themselves in situations of vulnerability, isolation and, in certain cases, exclusion.

In the present study, were found limitations in relation to procedures of participant selection and final sampling. Community Nursing professionals were chosen because they are in regular contact with patients and their caregivers, objects of empirical study. Sampling was based on three filters, namely: companions of people attended at institutions that fulfilled the inclusion criteria, who performed (according to professional judgment) the caregiver role and agreed voluntarily to participate in the study. Two problems emerged from this selection: 1) the sample of caregivers was selected subjectively and based on discretion of the professional who provided the questionnaires, y 2) questionnaires were provided only for those who accompanied the diagnosed person to the institution, which prevented access to a larger sample.

However, the findings of this study highlight the benefits of creating associative spaces of community interaction and mutual support, and the importance of psychoeducational workshops in order to understand the illness processes, develop coping strategies and empower caregivers and the people cared for.

Therefore, public health authorities must focus their efforts on the social welfare of the population they serve. In this sense, it would be advisable to support the following proposals: Encourage coordinated support networks between the areas of health education, nursing and community services, and increase mental health programs in the community by jointly favoring combined treatments for the recovery and stability of people with SMD hence, releasing the burden of caregivers. The present study mentions the need to promote community-based day hospitals where users can go in order to receive health treatment and expand their social circuit; collaborate since health administration in the creation of associations of relatives of people with SMD, of users, or mixed associations in order to boost the support networks available and generate new ones, and implement complementary programs to those articulated with public health; and connect rural areas or those of scarce resources with metropolitan geographic areas for the reduction of family burden levels of caregivers and for the recovery and psychiatric stabilization of people with illnesses.

Ultimately, the associationism, social support programs in the community and rehabilitative socio-health activities are protective factors, and the lack of structure for their development can generate risk practices for both caregivers and people with illnesses and have impact on community deterioration.

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ESTUDIO 2. Risk factors associated with the family care of people with serious mental illness

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Risk factors associated with the family care of people with serious mental illness

Ángela Carbonell [1], José-Javier Navarro-Pérez [2], Maria-Vicenta Mestre [3]

[1] Department of Social Work and Social Services, University of Valencia (Spain)
[2] Inter-University Research of Local Development (IidL), Department of Social Work and Social Services, University of Valencia (Spain)
[3] Department of Basic Psychology, University of Valencia (Spain)

Correspondence:
Department of Social Work and Social Services
Tarongers Avenue 4B,
46022 Valencia
Office 1D19 - University of Valencia (Spain)
Angela.Carbonell@uv.es

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Abstract

Background: The aim of the present study is to analyse the variables associated with the family care of people diagnosed with serious mental illness.
Material and Methods: A cross-sectional study was carried out involving caregivers of people with serious mental illness (SMI) who were known to the mental health services in Valencia (España) and associations for those with SMI. The sample comprised 417 caregivers who completed a sociodemographic questionnaire and the Zarit Burden Interview. Bivariate analyses (t-test, analysis of variance and Pearson correlation) were performed, as was a multiple linear regression model. Values of $p < .05$ were considered significant. The study was carried out in accordance with the recommendations of the ethics committees of the participating institutions.
Results: The statistical analyses showed significant associations between the sociodemographic and clinical variables of the caregivers and patients and the burden felt by caregivers of people with SMI. The importance of both formal and informal social support stands out as a protective factor against the consequences of the illness's impact on the main caregiver.
Conclusions: The role of spaces of mutual support is crucial. The results suggest that family psychoeducational programmes should be created, applied and evaluated in all mental healthcare services so as to reinforce training in mental health matters and provide support and assessment to caregivers in order to ease their burden.

***Key words:** Care, social support, mental health, associationism.*

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4.2.2. Introduction

Mental healthcare has undergone far-reaching epistemological and practical changes, representing a long and complex historical and cultural process. Indeed, the

World Health Organization has for many years been questioning the role of psychiatric institutions and healthcare processes dealing with mental health. Until the mid-twentieth century the only treatment provided by psychiatry was hospitalization for indefinite periods of time. The appearance of new community healthcare models for people with mental illness, based on criteria of quality of life and decent care, and the incipient development of psychopharmacology marked the beginning of a move towards psychiatric deinstitutionalization (Ahmed et al., 2018) involving the closure of psychiatric hospitals and the release of people with serious mental illness (SMI) into the community (Fauble, 2016).

Despite the fact that the mental healthcare system in Spain has fought to provide the necessary support services, the family continues to be the main source of care for people with SMI. Although family care can have a positive impact on the rehabilitation and recovery of these people, the scientific literature is rich in studies that show that their caregivers can experience strong feelings of burden and objective and subjective distress (Bui et al., 2018) as a result of their many responsibilities and the exhaustion these induce. Apart from the mental and emotional impact, the care burden involves anxiety-provoking aspects such as economic cost, shame, stigma and feelings of guilt and self-pity.

Taking into account the negative repercussions of psychiatric family care, studies have analysed how the care burden can be influenced by the sociodemographic and clinical characteristics of the patients and caregivers and how these affect the caregivers' quality of life (Ribé et al., 2017). The feminization of care makes it difficult to provide significant evidence of the burden according to gender (Jansen et al., 2015). Nevertheless, it is the mother who usually performs the task as a moral obligation in a patriarchal society, which makes it difficult to reconcile work and care. A study carried out in Spain showed that the parents of sick people feel greater levels of burden and worry more about their future than other family members (Cirici et al., 2018). Studies have associated the lengthy nature of chronic illnesses and the ageing of caregivers with an enormous family burden, revealing higher levels of burden in caregivers whose family members have been sick for a long time or whose illness began at an early age, and with less autonomy and more active symptoms that require a greater number of hospitalizations (Rhee & Rosenheck, 2019; Wong et al., 2012). Other demographic characteristics of the caregivers, such as economic income and level of education, have been shown to correlate with their psychological and physical burden. Social support, however, is considered to be a protective factor (Haselden et al., 2018) since it makes it possible to understand the compensation and adjustment mechanisms used to deal with the difficulties of care and to reduce the harmful effects that emerge as a result of providing continuous care for someone.

The aims of this study are (1) to identify the characteristics of the caregivers of people with SMI, (2) to identify the level of burden, and (3) to analyse the variables associated with family care in mental health.

4.2.3. Material and Methods

A descriptive cross-sectional study of family caregivers of people with SMI was carried out.

Participants

The study population consists of family caregivers. The inclusion criteria were (1) resident in Valencia (España), (2) caregiver of a person diagnosed with an SMI according to the DSM-5 and responsible for the associated tasks, (3) age ≥ 18 years, (4) no psychiatric history, (5) family member or relative, (6) care ≥ 6 months, (7) absence of remuneration for the care provided, and (8) voluntary participation in the study. Those who did not complete the questionnaires correctly and those who declined to participate were excluded. 417 family caregivers of people with SMI were included as participants in the study.

Instruments

The main instrument used was the Zarit Burden Interview (ZBI) (Zarit & Zarit, 1987) as adapted into Spanish by Martin et al. (1996), which measures the extent of the caregiver's burden. Although this has mainly been used with the caregivers of people with dementia, the extensive literature (Loi et al., 2015; Martin-Carrasco et al., 2016) endorses its use also with caregivers of people with mental illness. It consists of 22 items recorded using a Likert scale from 0 (never) to 4 (nearly always). The results add up to a total score of between 0 and 88 points. Higher scores indicate greater caregiver distress. For the present study the scale obtained a Cronbach's alpha coefficient of .91.

Included were the sociodemographic characteristics of the caregivers (sex, age, marital status, relationship to the sick person, employment situation, presence of health problems, active associationism, psychoeducational interventions and geographical setting) and of the people cared for (age, sex, diagnosis, number of years since SMI was diagnosed, degree of disability and care received).

Procedure

The participants were recruited via mental healthcare facilities and associations of patients and family members of people with SMI in Valencia (España). An appeal was made for volunteers and information about the study was provided. Once the participants had been selected, individualized interviews were arranged, in which the Spanish version of the ZBI questionnaire was administered and sociodemographic and clinical details collected. Participants received no monetary compensation for taking part in the study. Data were collected between June and December 2018.

The study was carried out in accordance with human rights protection protocols and satisfied the ethical requirements for research approved by the institutional review board before the participants were recruited. The family caregivers were sent a letter that explained the details of the study and informed them that they had the right to interrupt or leave the study at any time and for any reason, in accordance with the Declaration of Helsinki. All participants gave their informed consent in writing before data were collected.

Data Analysis

The IBM SPSS Statistics 25 package was used for the data analysis. The level of statistical significance was established as $p < .05$. Descriptive statistics (percentages, means and standard deviations) were used to describe the sociodemographic characteristics of the caregivers and the people being cared for. The relation between sociodemographic characteristics and burden was identified. Inferential analysis involving t-tests and ANOVAs was used to identify statistically significant differences between the ZBI and the nominal variables. Correlations between continuous variables were analysed using the Pearson correlation coefficient. Finally, those variables that showed a statistically significant association were included in a stepwise multiple linear regression analysis to determine the predictive factors for caregiver burden.

4.2.4. Results

The Participants' Sociodemographic Characteristics

The study sample comprised 417 family caregivers of people with SMI, 72.2% of whom were women. Ages ranged between 18 and 89 years, with an average of 60.82 (SD = 13.46). Generally speaking, the participants in the study were the parents of those looked after (78.7%) and were married (52.8%) or divorced (14.9%). Most were not in paid employment (59.7%) and 49.2% had previously been caregivers of another sick person. The participants' sociodemographic characteristics are listed in Table 9.

Table 9

Sociodemographic characteristics of the study participants

Variable	n = 417
Age (years)	60.82±13.46
Sex (female)	72.2%
Marital status	
Married	52.8%
Divorced	14.9%
Single	12.1%
Widow(er)	21.5%
Paid employment (yes)	40.3%
Presence of health problems (yes)	41.2%
Relation to the person looked after	
Parent	78.7%
Sibling	12.9%
Daughter/son	4.1%
Intimate partner	3.4%
Aunt/uncle	1%
Active associationism (yes)	14.1%
Previously cared for another relative (yes)	50.8%
Psychoeducational training (yes)	54.4%

Source: Own.

The general profile of the person receiving care was male (69.8%) with an average age of 38.78 years (SD = 12.88; range = 16-80 years). All those being looked after had been diagnosed with an SMI – according to DSM-5 criteria – by psychiatric staff belonging to the public healthcare services in Valencia (España). The most common diagnoses were schizophrenia (62.1%), personality disorder (14.9%) and bipolar disorder (12.2%), and patients had had the illness for an average of 17.22 years (SD = 13.08). In addition, 49.4% had a recognized disability that affected their personal autonomy to a high degree.

Caregiver Burden and Associated Variables

The overall average score for burden was 45.79 (SD = 17.09, range 10-80), with 14% of caregivers registering no burden at all. The rest showed light (24.9%) and intense (61.1%) levels.

Comparison of means tests indicated there were variables with values of statistical significance $p > .05$, which included marital status, having a chronic illness, having previously cared for someone else, and family relationship. The analysis established differences depending on the participants' sex and care burden ($t = 1.932$; $p < .05$), with men obtaining an average score of 48.53 (SD = 18.06) and women 44.76 (SD = 16.64). Caregivers in paid employment felt significantly higher levels of burden (M = 49.96; SD = 17.44) than those who were not active ($t = -4.133$; $p < .05$). Lower levels of burden were associated with caregivers who had taken part in psychoeducational interventions ($t = 12.978$; $p < .05$) and/or were members of an association ($t = 13.724$; $p < .05$). Geographical setting was also significantly related with the caregiver's burden ($t = -5.962$; $p < .05$), with caregivers living in metropolitan and rural areas obtaining an average score of 50.04 (SD = 16.33) compared to the 40.32 (SD = 16.55) of those living in towns and villages.

As far as the variables for the person looked after are concerned, the t-tests indicated that there were differences in the level of burden depending on their sex ($t = -2.096$; $p < .05$), with caregivers who looked after women showing higher levels (M = 48.37; SD = 16.14) than those who looked after men (M = 44.66; SD = 14.41). Similarly, the caregivers of people who received continuous care in public mental healthcare facilities had an average burden score of 33.29 (SD = 14.143), while those who looked after people who did not had an average of 51.97 (SD = 14.93) ($t = -12.411$; $p < .05$). The descriptive inferential analysis found that the mental illness diagnosis of the person looked after also had a significant effect on the caregiver burden, $F(6, 413) = 3.974$, $p < .05$, $\eta^2 = .056$), with very high levels being found in caregivers of people with personality disorder (M = 54.31; SD = 12.49) compared to other diagnoses such as schizophrenia (M = 43.27; SD = 17.14).

Pearson correlation analysis (Table 10) found negative associations between the care burden and age ($r = -.147$; $p < .05$), with levels of burden diminishing as the caregiver's age increases. No significant relations were found for the disability and age of the person cared for. However, the years of duration of the illness correlated positively with burden ($r = .175$; $p < .05$).

Table 10

Pearson correlations for the dimensions of the variables analysed

	ZBI	**Age**	**Age SMI**	**DD**
Age	-.147**			
Age SMI	.059	.216**		
DD	.082	.209**	.465**	
Years of illness	.175**	.301**	.478**	.321**

ZBI = Zarit Burden Interview; Age SMI = Age of person cared for; DD = Degree of disability.

**. The correlation is significant at a level of 0.01 (bilateral).

Source: Own

To determine which variables contributed with significant unique predictive variance, the significant predictors were included in a multiple linear regression. As can be seen in Table 10, six regression models were constructed, revealing that the factors significantly associated with the highest burden scores were (1) participation in psychoeducational interventions, (2) associationism, and (3) continuous healthcare. The regression was highly significant (adjusted $R^2 = 0.41$; F = 3, 97.214; $p < .05$).

Table 11

Linear regression of the burden of the family caregiver of people with SMI

	Unstandardized coefficients		**Standardized coefficients**		
Model	B	Standard error	Beta	**t**	**Sig.**
(Constant)	54.739	.873		62.715	.000
Psychoeducational training	-14.614	2.134	-.299	-6.848	.000
Associationism	-11.659	1.852	-.340	-6.296	.000
Continuous healthcare	-4.838	1.991	-.133	-2.430	.016

* Dependent variable: ZBI

4.2.5. Discussion

The family is the main support system and takes on the responsibility of caring for the patient in the community. The present investigation provides new evidence of the magnitude of the care burden, identifies factors associated with it and analyses the sociodemographic profile of 417 family caregivers of patients with SMI treated in different healthcare services in Valencia (España)

As far as the study's first aim is concerned, the sociodemographic characteristics of the sample are similar to those in other studies on caregivers of patients with SMI (Bansal et al., 2017; Tabeleão et al., 2014), in which the predominant profile is that of a woman just entering old age, married, without paid employment and with no chronic pathologies. Considering this, it is clear that there is inequality in the provision of care since it is mainly carried out by women, and this makes these women a collective that is vulnerable to the consequences resulting from the work they do. 72.2% of care is in the hands of women. Although the results of this study indicate that it is more usual for them to take on the task of caring (M = 44.76), the men obtained a higher average score (M = 48.53) for burden. Meanwhile the profile of the person with SMI matches that in Kate et al. (2013): male, adult, diagnosed with schizophrenia, living with parents, and with the mother as the mainstay of care and attention.

The analysis of caregiver burden produced an average score of 45.79, and three-quarters of the population surveyed registered intense levels of burden on the ZBI, revealing that the caregivers of people with SMI felt a significant burden similar to that found in other studies in the literature (Shamsaei et al., 2015; Tabeleão et al., 2014), which warn that this population could be at risk of being overwhelmed.

In this study the caregiver burden is associated with sex and age, with the highest levels being found among male and younger caregivers, unlike in other recent investigations (Jagannathan et al., 2014; Souza et al., 2017) that indicate that looking after women and older patients are sources of stress and factors predictive of burden. Following Blanco et al. (2018), this could be because inexperience and the opportunity costs of care may cause a feeling of burden in younger male caregivers. Another factor associated with caregiver burden was the problem of reconciling working life with care (Stewart et al., 2018). Both the existing literature (Zanetti et al., 2018) and the results of this investigation describe characteristics typical of SMI (diagnosis, prognosis, years of illness, etc.) as being factors that induce feelings of burden in the caregiver. Hence the findings relate disorders with more complex symptoms (such as personality disorder) and the years of duration of the illness with greater levels of distress in the caregiver.

Despite the fact that the literature has focused mainly on the pathogenic factors of care, the results of the regression analysis showed that the variables connected with formal and informal social support were the most important mediator variables for caregiver burden (Navarro-Pérez & Carbonell, 2018; Ribé et al., 2017). Access to continuous specialist healthcare, associationism and psychoeducational interventions for family members determined the burden levels of the caregivers, working as protective factors against the stressful impact of providing care. As argued in earlier studies (Chen et al., 2019; Kate et al., 2013; Navarro-Pérez & Carbonell, 2018), caregivers who perceive that they obtain sufficient support from institutions, family members and friends have a better quality of life and feel less distress in connection with the work they do.

Limitations

The present study is subject to two limitations. The cross-sectional nature of the investigation made it possible to establish a predictive model for burden. However, longitudinal studies are more suitable for verifying the predictive factors of caregiver burden. Another important limitation was the non-existence of specific resources aimed at the caregivers and family members of people with SMI. This also meant that the sample was obtained in two blocks: from family associations of people with SMI and the public mental healthcare services whose family members agreed to participate in the study.

Despite the above limitations, this study has revealed a significant relationship between the sex, age and employment situation of the caregivers, the age and diagnosis of the patient, the years of duration of the illness and the caregiver burden of those looking after people with SMI. Social support stood out as a protective factor for care in a wide, representative sample of caregivers, allowing interventions to contribute to lessening the burden felt by the caregivers of people with SMI.

Today the support the public system gives is not enough. Although the government does provide resources for people with SMI and their family members, these resources are still limited and poorly funded. Families stand in for the lack of public resources earmarked for people with SMI. Thus patients remain with their families and this makeshift arrangement becomes an end in itself, even though the actual root of the problem is not tackled. Instead, problems are dealt with as they appear. The family is not given even the minimum resources to provide suitable care in each case. The consequences of informal care for the people that provide it continue to be a common challenge, and the response needs to involve the creation of real integrated healthcare policies aimed at both people with SMI and their caregivers. The state should promote public policies providing real support for family members who perform these tasks for other family members. This support should include rehabilitation services, psychosocial care, education, and training in carrying out both care and self-care tasks and be provided not only through the mental healthcare services but also via other psychosocial healthcare facilities.

4.2.6. References

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ESTUDIO 3. The care crisis in Spain: an analysis of the family care situation in mental health from a professional psychosocial perspective

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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

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

4.3.1. Abstract

Objective: 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.

Material and Methods: The empirical process involved three qualitative techniques and 37 experts from different regions of Spain. Interviews were conducted with 22 professionals who take care of people with mental illness in various public facilities throughout the country. To create the interview script, a focus group of eight social workers was set up, and a group of experts was also formed to validate the information generated in the interviews using a system of categories and subcategories. The interaction effects of the focus groups allowed methodological triangulation whereby the results from the groups of experts expanded and strengthened the interview findings.

Results and Conclusion: The results of the empirical process indicate a need to remodel the mental health care system, which is characterized by underfunding and lack of government support, and to urgently design social protection policies to guarantee the welfare of the mentally ill and recognize the role of the caregiver.

Keywords: Mental health, caregiver, health care model, overload, social work, focus groups, interviews.

4.3.2. Introduction

Over time mental health care has undergone far-reaching epistemological and practical changes, representing a long and complex historical and cultural process. Many years ago, this led the World Health Organization (WHO) to begin to question the role of the psychiatric institutions and care processes in mental health. Until the mid-twentieth century, psychiatric treatment consisted of locking people up for indefinite periods of time.

The appearance of new community models of mental health care based on quality of life and decent care together with the incipient development of psychopharmacology signalled the beginning of the psychiatric deinstitutionalization movement (Ahmed et al., 2018). This advocated the closure of psychiatric hospitals, the territorialization of mental health services and the reintegration of the mentally ill back into the community (Fauble, 2016; Zegwaard et al., 2015). Reform would guarantee the incorporation of new therapeutic designs and the creation of more effective, more caring and more humane resources supported by the human rights movement (Juan-Porcar et al., 2015).

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 (WHO, 2017). Mental health started to become as much of a priority in Spain as in other European countries (Helsinki Declaration, 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 (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 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 & Santos, 2016). Deinstitutionalization has therefore always meant a lower quality of life for caregivers because of the impact it has on their lives (Guedes et al., 2017) due to the ever-growing number of responsibilities they have to take on and the subsequent deresponsibilization of the state (Soto et al., 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 Steinet al. (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. This has become apparent in Spain over recent years with the dismantling and freezing of Act 39/2006 of 14 December on the Promotion of

Personal Autonomy and Care of People in a Situation of Dependence, which (1) guaranteed universal rights to anyone who needed care for prolonged periods of time, (2) established a series of services to meet people's needs, and (3) recognized the right to a financial benefit to pay for care in the family environment and as support for non-professional caregivers. The Spanish government's cost-containment policies and the underdevelopment of public care services have led to a reprivatization of care in households (Guillén et al., 2016), the casualization of family caregivers and a new burden for families and especially for women to carry (Mosca et al., 2017; Peña-Longobardo et al., 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 & Yildiz, 2018). Those with serious mental health problems are defined as a population likely to need long-term care and assistance (Alexander et el., 2016). The scientific literature is rich in studies (Jagannathan et al., 2014; Krishnan & Sood, 2017) that analyse 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 care is not only associated with negative consequences but also with subjective gains and satisfaction (Kulhara et al., 2012), it is a great devourer of time and opportunity in many areas of life. Authors such as Hong and Harrington (2016), Kim et al. (2015), Opara et al. (2012) and Villalobos et al. (2017) have shown that the prolonged care of another person brings personal, family, work and social changes along with negative consequences for the physical and psychological health of the caregiver. Various studies (Hayes et al., 2015) conceptualize as "caregiver syndrome" the combination of terms referring to all the negative consequences that caring for a dependent person has for the person caring for them. Recent investigations (Gater et al. 2014; Perlick et al., 2016) indicate that isolation, insomnia, psychological discomfort, desperation and uncertainty, overload, stress, physical problems, difficulty in meeting the costs of the illness (medical treatment, medicines, resources), precarious employment, anxiety and feelings of discontent with life are objective and subjective consequences of this syndrome and have direct and indirect effects on the quality of the life of the caregiver, the person with mental illness and the family unit. Studies carried out in Turkey (Durmaz & Okanli, 2014) and other countries (Caqueo-Urízar et al. 2014; Gelkopf & Roe, 2014) report that positive and negative factors of mental illness such as non-adherence to treatment, the stigma, suicidal ideation and behavioural disorders are some of the most frequent challenges faced by caregivers and have a significant impact on the perceived burden.

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 et al. 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 shortfalls of the mental health care model from a professional psychosocial perspective.

4.3.3. 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. This investigation is based on a qualitative approach and uses two different techniques. First, a focus group (FG1) was set up to construct the interview script. This 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 fully explore the extent of family responsibility in mental health and identify shortfalls in the mental health care model. And second, interviews were carried out with 22 professionals whose work it is to care for people with mental illnesses in various health facilities throughout the country. Another focus group (FG2) of experts was set up to validate the process of categorizing information from the interviews (See Table 12).

Table 12

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	· 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	· 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	· Professionals occupying management positions in public mental health services · Managers in charge of other professionals · More than 10 years' professional experience in the post

Participants

The total sample was made up of 37 professionals specializing in mental health from a variety of Spanish regions. FG1 comprised eight social workers with jobs in different public mental health facilities (public health system, NGOs, centres 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. Once the script was designed, in-depth interviews were conducted with the different professional profiles that make up the multidisciplinary mental health teams: psychologists, psychiatrists, social workers and nurses. Information saturation was reached after 22 semistructured interviews with these professionals, following gender parity criteria.

To validate the categorizations analysed in the interviews, FG2 met for three sessions. 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).

A total of 398 possible participants from all the autonomous regions of the country were contacted. Of these, 149 satisfied the inclusion criteria shown in Table 13 and agreed to take part in the study. Participants for interviews and focal groups were chosen randomly according to professional profile, autonomous region and sex in order to guarantee gender parity. Finally, a total of 37 participants from all 17 autonomous regions of Spain were identified. The regions with greater population had greater representation in the sample interviewed.

Table 13

Description of the study's participants

Code	Technique	Occupation	Sex	Experience	Region
TS1	Focus group 1	Social worker	Female	8 years	Madrid
TS2	Focus group 1	Social worker	Male	12 years	Galicia
TS3	Focus group 1	Social worker	Female	11 years	Galicia
TS4	Focus group 1	Social worker	Female	23 years	Aragon
TS5	Focus group 1	Social worker	Female	6 years	Catalonia
TS6	Focus group 1	Social worker	Male	8 years	Valencian Com.
TS7	Focus group 1	Social worker	Male	13 years	Murcia Region
TS8	Focus group 1	Social worker	Male	15 years	Valencian Com.
IC1	Interviews	Psychiatrist	Female	16 years	Andalusia
IC2	Interviews	Psychiatrist	Female	6 years	Madrid
IC3	Interviews	Psychiatrist	Male	11 years	Asturias
IC4	Interviews	Psychiatrist	Male	17 years	Catalonia
IC5	Interviews	Psychiatrist	Female	15 years	Aragon
IC6	Interviews	Clinical psychologist	Male	6 years	Castile-Leon

IC7	Interviews	Clinical psychologist	Female	7 years	Valencian Com.
IC8	Interviews	Clinical psychologist	Male	9 years	Canary Islands
IC9	Interviews	Clinical psychologist	Male	24 years	Castile-La Mancha
IC10	Interviews	Social worker	Male	32 years	Andalusia
IC11	Interviews	Social worker	Female	6 years	Andalusia
IC12	Interviews	Social worker	Male	8 years	Madrid
IC14	Interviews	Social worker	Male	15 years	Balearic Islands
IC15	Interviews	Social worker	Female	13 years	Extremadura
IC16	Interviews	Nurse	Male	15 years	Madrid
IC17	Interviews	Nurse	Male	7 years	Catalonia
IC18	Interviews	Nurse	Female	27 years	Cantabria
IC19	Interviews	Nurse	Female	26 years	Catalonia
IC20	Interviews	Nurse	Female	14 years	La Rioja
IC21	Interviews	Assistant nurse	Female	12 years	Valencian Com.
IC22	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

Procedure

The convenience sampling technique was used to obtain the sample of professionals to participate in the study. Authorization to contact these different experts was sought from the relevant authorities. Once authorization had been granted by the autonomous administrations in all regions of the country, emails were sent to each of the professionals who satisfied the inclusion criteria and were willing to take part in the study until information saturation was reached.

The opinions expressed and information supplied in the interviews and focus groups were collected via video and audio recording, the consent and authorization of all participants having been requested and obtained beforehand. 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.

FG1 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 finished, 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. FG2 ratified or refuted the categorizations and the quality of the information derived from the interviews.

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

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 and social workers working first individually and then together, a code manual was compiled to organize and establish connections between categories. In case of disagreements between coders, a third researcher was on hand to review any issue when necessary. 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, 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).

4.3.4. 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 14). 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.

Table 14

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.

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" (IC21)

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 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". (IC13)

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". (TS8)

> "If someone in the family falls ill, the woman assumes it's going to be her job to look after them". (IC12)

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". (IC1)

> "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". (TS4)

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 centres.

> "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". (IC6)

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 centres (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 centres 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 centres 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". (IC18)

> "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". (TS8)

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 health professionals specialisin with perhaps more specific training in these subjects, in intermediate or community resources, who'd be able to work with them". (IC5)

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". (IC14)

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". (IC10)

> "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". (IC22)

> "Spaces need to be provided where the patient can go and live, so the family doesn't have to look after them". (TS2).

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 centred 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". (IC13)

> "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". (TS1)

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)

4.3.5. 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 et al., (2016) and Martín (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 et al., 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 et al., 2018; Yu et al., 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 health care 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 others 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 towards the person's recovery and their full social inclusion (Davidson, 2016; Lietz et al., 2014; Kidd et al., 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.

4.3.6. 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.

4.3.7. References

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ESTUDIO 4. Challenges and barriers in mental healthcare systems and their impact on the family: A systematic integrative review

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REVIEW ARTICLE

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

Ángela Carbonell MSW, PhD Candidate[1] | **José-Javier Navarro-Pérez PhD, Associate Professor**[1] | **Maria-Vicenta Mestre PhD, Professor**[2]

[1]Inter-University Research of Local Development (IidL) and Social Work and Social Services Department, University of Valencia, Valencia, Spain
[2]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

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

4.4.1. Abstract

Objective: 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.

Material and Methods: 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.

Findings: 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.

Conclusion: 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: Treatment Gap, Health Systems, Mental Health, Family Care.

4.4.2. Introduction

The World Health Organization (WHO) (2007) defines a health system as the sum total of all the organizations, 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 et al., 2017) into four separate groups, which in turn are usually categorized 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 et al. (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 et al. (2016) and Drake et al. (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 organizations 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 et al. (2019) and Salisbury et al. (2016) identify latent challenges such as a lack of consensus on definition, the implementation of deinstitutionalization, 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 decentralization 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 Kardorffet al. 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 et al. 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 families from the financial burden associated with illness and healthcare (Kristensen et al., 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 wellbeing and quality of life of people with mental illness and their family caregivers. For this reason, the present study aims to summarize the literature and analyse the challenges and barriers in mental health systems and their impact on the family.

4.4.3. 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 & Knafl, 2005). The review was carried out in accordance with the basic principles of systematic review – breadth, rigour and transparency (Mallett et al., 2012) – thus ensuring the synthesis of the evidence and the methodological rigour of the investigation.

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 (SJR) quartiles and impact factors as a reference.

The exclusion criteria were: a) studies on the elderly 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.

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 15. Afterwards, the bibliography sections of the eligible studies we recovered were used to identify other relevant studies.

Table 15

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*

Data Extraction and Synthesis

A number of strategies were used to improve analytical rigour. For the identification of articles, the process included the following 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 (Finfgeld-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 categorization 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).

Quality Evaluation of the Studies

High-quality journals contribute significantly to academic development in a particular field (Judge et al., 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 organizations 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 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 (CCRBT) (Higgins et al. 2011) was also used to assess the methodological quality of studies that included quantitative results. The CCRBT 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 et al. 2013), any mixed-method studies were evaluated using both the CCRBT and the CASP Qualitative Checklist.

The methodological quality 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 A.

4.4.4. 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.

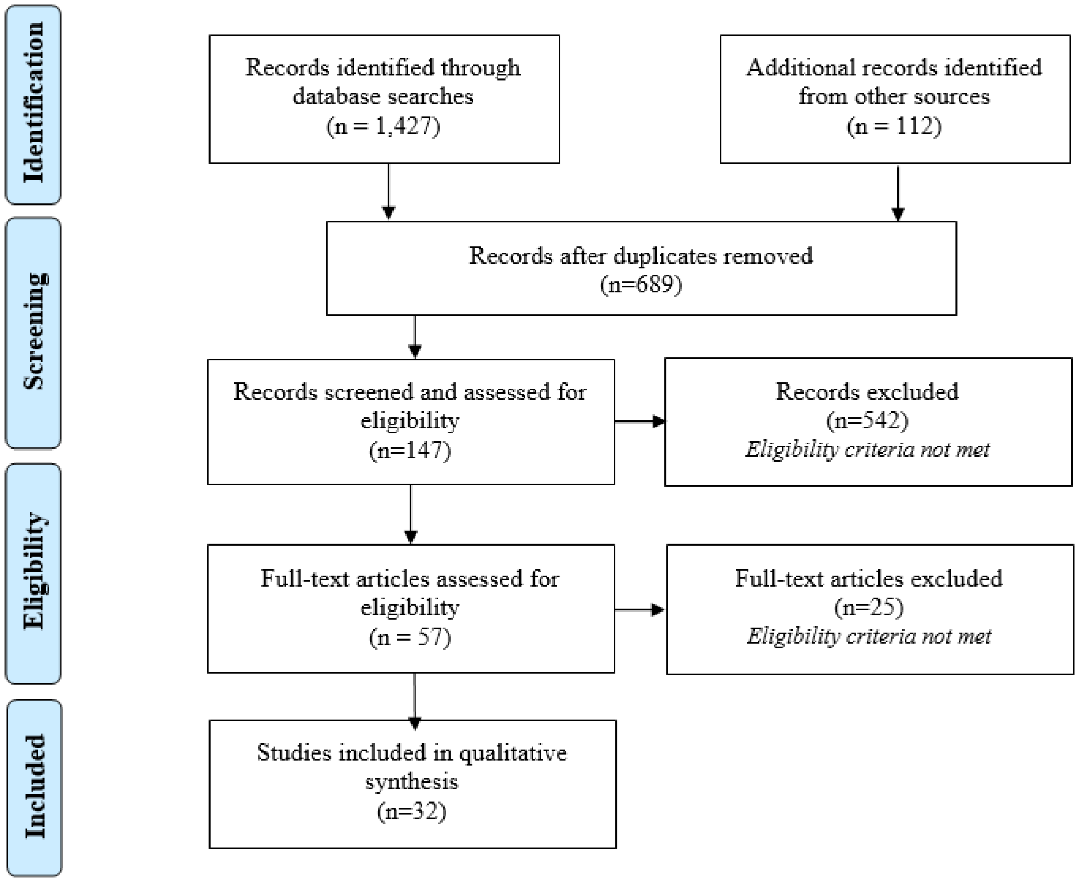

Figure 1. PRISMA 2009 flow chart (Moher et al., 2009)

Description of the Included Studies

Table 16 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, 8 cross-sectional quantitative studies and 3 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, 2 studies (6.3%) compared different populations and 4 (12.3%) covered the entire world population. Of the studies carried out on specific populations, 41.7% involved LMICs and 58.3% HMICs.

Table 16

Methodological and quality characteristics of the papers analysed

Author (year)	Country	Study design	Sample	Journal	Database index	JIF	MQ
Abayneh et al. (2017)	Ethiopia*	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**	Qualitative	29 service providers and policy makers	Administration and Policy in Mental Health and Mental Health Services Research	JCR	2.681	High
Ali & Agyapong (2015)	Sudan*	Mixed-methods	103 caregivers and 6 consultant psychiatrists	BMC Health Services Research	JCR	1.932	Low risk of bias
Ambikile & Iseselo (2017)	Tanzania*	Qualitative	7 service providers, 7 people with SMI and 16 caregivers	BMC Psychiatry	JCR	2.666	High
Arandjelovic et al. (2016)	Australia**	Review		Australian & New Zealand Journal of Psychiatry	JCR	5.000	High
Athié et al. (2016)	Brazil**	Mixed-methods	18 health managers and 24 professionals	BMC Health Services Research	JCR	1.932	Low risk of bias
Azman et al. (2019)	Malaysia**	Qualitative	15 family caregivers of people with SMI	International Social Work	JCR	0.603	High
Balhara et al. (2016)	France, Spain, Israel** and India*	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*	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**	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**	Quantitative	95 caregivers of people with SMI	Journal of Gerontological Social Work	JCR	0.849	Low risk of bias
Hanlon et al. (2017)	Ethiopia*	Qualitative	7 service providers and 10 administrators and facility heads	International Journal of Mental Health Systems	JCR	1.986	High
Kaur & Pathak (2017)	India*	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 & Khan (2016)	Pakistan*	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**	Quantitative	1800 inhabitants of Japan aged 18 to 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**	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*	Qualitative	14 service providers	Health & Social Care in the Community	JCR	1.573	High
Martin et al. (2017)	All countries	Review		International Journal of Social Psychiatry	JCR	1.370	High
Rand et al. (2019)	England**	Quantitative	387 caregivers of people with SMI	Health & Social Care in the Community	JCR	1.573	Low risk of bias
Sahithya & Reddy (2018)	India*	Review		International Journal of Culture and Mental Health	SJR	0.327	Moderate

Saymah et al. (2015)	Gaza*	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 et al. (2018)	Brazil and Spain**	Review		Physis	SJR	0.243	Moderate
Tsui & Tsang (2017)	China**	Qualitative	8 people with SMI and 8 caregivers	Psychiatry Research	JCR	2.208	High
Valentini et al. (2016)	Germany**	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 et al. (2019)	USA**	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**	Qualitative	13 users of mental health services aged over 18	Community Mental Health Journal	JCR	1.159	High
Wong et al. (2016)	Japan**	Qualitative	7 mental health social workers	Social Work in Mental Health	SJR	0.232	High

*Low- and middle-income countries; **High- and middle-income countries; JIF = Journal Impact Factor 2018; MQ = Methodological Quality.

Barriers in Mental Healthcare Systems

Five descriptive categories were found in relation to the challenges and barriers in mental healthcare systems: (1) structural barriers, (2) health culture, (3) illness costs, (4) rehabilitation management, and (5) 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 17.

Table 17

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 mentally ill by the public health system
Health culture	Labelling Widespread lack of knowledge about mental illness Underuse of services by users Use of ritualized 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 medicalization Low-impact combined treatments Investment in psychiatric macro-institutions Subsidiary care
Care provision: families	Overload Opportunity costs Little social support Barriers to family participation

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, 2015), 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 et al., 2019; Hanlon et al., 2017; Keynejad et al., 2016). According to Malik & 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 et al. 2019). In Brazil, even though today it is categorized 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 et al., 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 et al., 2017; Kaur & Pathak, 2017; Keynejad et al., 2016; Saymah et al., 2015).

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 stigmatized (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., 2016; Hanlon et al., 2017; Kaur & Pathak, 2017; Keynejad et al., 2016; Kikuzawa et al., 2019; Leng et al., 2019; Mantovani et al., 2017; Vigo et al., 2019; Walter et al., 2019; Wonders et al., 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 et al., 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 stigmatization. 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, 2016; Kikuzawa et al., 2019). Kaur & Pathak (2017) believe that the definitions of mental illness used in India are out of date and should be reconsidered. Along similar lines, Tsui & 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.

Illness costs. The study carried out by Kóvacs et al. (2018) estimates that the average annual medical cost of schizophrenia is 5800€ 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 & 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, hospitalization, etc.). Kóvacs et al. (2018) report that medication costs account for less than 25% of the direct costs of medical care per patient in Europe, while hospitalization 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; Sahithya & Reddy, 2018; Malik & Khan, 2016). 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 hospitalization represents the biggest direct cost for mental health and is unaffordable for families and for the system itself (Malik & Khan, 2016; Kovacs et al., 2018; 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 hospitalization 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).

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., 2017; 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 & 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 & Pathak (2017) and Sahithya & 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, 2015; 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 deinstitutionalization, 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 et al., 2019; Valentini et al., 2016) due to long waiting times (Ali & Agyapong, 2015), 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.

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 et al. 2016). Limited government spending on the development of mental health services biases treatments towards medicalized and institutionalized 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 & 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 dehumanization 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 (Ambikile & Iseselo, 2017; Akbari et al., 2019). 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 decentralization 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.

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; Calvó-Perxas et al., 2018; Greenfield et al., 2018; Leng et al., 2019; Rand et al., 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 Calvó-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 recognized 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 et al. (2017), this is due to the exclusion, disempowerment and invisibilization 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).

4.4.5. 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 et al., 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 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 et al., 2018).

Like in other investigations (Pescosolido, 2019; Saxena et al., 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 wellbeing 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 wellbeing.

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 et al. (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, wellbeing 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 socioeconomic 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 et al. (2019) and Thornicroft et al. (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.

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.

4.4.6. 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 wellbeing 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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4.4.8. Appendix A

Table 18

Quality assessment of the qualitative research design

CASP checklist*	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**TOTAL**
Abayneh et al.	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	High
Ali & Agyapong	Y	Y	Y	Y	Y	C	Y	Y	Y	N	High
Akbari et al.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
Ambikile & Iseselo	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	High
Athié et al.	Y	Y	Y	Y	Y	N	Y	Y	Y	N	High
Azman et al.	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	High
Hanlon et al.	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	High
Mantovani et al.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
Saymah et al.	Y	Y	Y	Y	C	C	Y	Y	Y	C	Moderate
Tsui & Tsang	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	High
Valentini et al.	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	High
Walter et al.	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	High
Wonders et al.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
Wong et al.	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	High

Y= yes, N= no, C=can’t tell

*CASP checklist: (1) Was there a clear statement of the aims of the research? (2) Is a qualitative methodology appropriate? (3) Was the research design appropriate to address the aims of the research? (4) Was the recruitment strategy appropriate to the aims of the research? (5) Was the data collected in a way that addressed the research issue? (6) Has the relationship between researcher and participants been adequately considered? (7) Have ethical issues been taken into consideration? (8) Was the data analysis sufficiently rigorous? (9) Is there a clear statement of findings? (10) How valuable is the research?

Table 19

Quality assessment of the review design

CASP checklist*	1	2	3	4	5	6	7	8	9	10	TOTAL
Arandjelovic et al.	Y	Y	Y	N	Y	Y	C	Y	Y	Y	High
Balhara et al.	Y	Y	Y	N	Y	Y	C	Y	Y	C	Moderate
Bee et al.	Y	Y	Y	Y	Y	Y	C	Y	Y	Y	High
Kaur & Pathak	Y	Y	Y	N	Y	Y	C	Y	Y	C	Moderate
Keynejad et al.	Y	Y	Y	Y	Y	Y	C	Y	Y	Y	High
Kovacs et al.	Y	Y	Y	Y	Y	Y	C	Y	Y	Y	High
Martin el al.	Y	Y	Y	Y	Y	Y	C	Y	Y	Y	High
Sahithya & Reddy	Y	Y	Y	N	Y	Y	C	Y	Y	C	Moderate
Storm et al.	Y	Y	Y	Y	Y	Y	C	Y	Y	Y	High
Trapé et al.	Y	Y	Y	N	Y	Y	C	Y	Y	C	Moderate

Y= yes, N= no, C=can’t tell

*CASP checklist: (1) Did the review address a clearly focused question? (2) Did the authors look for the right type of papers? (3) Do you think all the important, relevant studies were included? (4) Did the review’s authors do enough to assess quality of the included studies? (5) If the results of the review have been combined, was it reasonable to do so? (6) What are the overall results of the review? (7) How precise are the results? (8) Can the results be applied to the local population? (9) Were all important outcomes considered? (10) Are the benefits worth the harms and costs?

Table 20

Assessment of bias risk in the quantitative research design

CCRBT questions*:	1	2	3	4	5	6	7	TOTAL
Ali & Agyapong	0	0	0	0	0	0	0	Low risk of bias
Athié et al.	0	0	0	0	0	0	0	Low risk of bias
Bitta et al.	0	0	0	0	0	0	0	Low risk of bias
Calvó-Perxas et al.	0	0	0	0	0	0	0	Low risk of bias
Greenfield et al.	0	0	0	0	0	0	0	Low risk of bias
Khan	0	0	0	0	0	0	0	Low risk of bias
Kikuzawa et al.	0	0	0	0	0	0	0	Low risk of bias
Leng et al.	0	0	0	0	0	0	0	Low risk of bias
Rand et al.	0	0	0	0	0	0	0	Low risk of bias
Saymah et al.	0	0	0	0	0	0	0	Low risk of bias
Vigo et al.	0	0	0	0	0	0	0	Low risk of bias

0: Low risk of bias; 1: High risk of bias; 99: Unclear risk of bias

*Assessment questions: (1) Random sequence generation; (2) Allocation concealment; (3) Blinding of participants and personnel; (4) Blinding of outcome assessment; (5) Incomplete outcome data; (6) Selective reporting; (7) Other bias.

CAPÍTULO 5. CONCLUSIONES Y CONSIDERACIONES FINALES

5.1. Conclusiones

La presente tesis doctoral analiza las barreras asociadas al cuidado familiar de la salud mental. Los objetivos generales que han motivado la realización de esta investigación son explorar los factores asociados a la sobrecarga de las cuidadoras familiares de personas con trastorno mental, conocer la percepción de los y las profesionales de la salud mental sobre el cuidado familiar y la gestión de las políticas públicas en este ámbito, y analizar los desafíos y barreras de los sistemas de atención a la salud mental y su impacto en la familia.

Los hallazgos de los cuatro estudios expuestos en el capítulo anterior sostienen que los factores individuales de las cuidadoras no son las únicas variables que contribuyen a la carga del cuidado familiar, sino que la influencia de una gran multitud de factores contextuales también son barreras que desafían el bienestar, calidad de vida e integridad de las personas que dedican su gran parte de su vida -o toda- al cuidado de la salud mental. Esta tesis aporta una visión general, pragmática y completa del objeto de estudio. De modo general, se desprende la importancia de considerar el contexto histórico, individual, social, cultural, económico y familiar que envuelve la enfermedad mental analizado en esta investigación para comprender el cuidado familiar de la salud mental, y reducir las repercusiones negativas derivadas de este.

Las investigaciones previas sobre cuidado familiar en salud mental han analizado con frecuencia la relación de las variables sociodemográficas y clínicas de las cuidadoras y las personas cuidadas y la sobrecarga. A partir del primer objetivo planteado, los dos estudios cuantitativos desarrollados de manera secuencial en la primera fase hallaron elevados niveles de sobrecarga en las cuidadoras. El segundo estudio revela que las variables individuales, tales como la edad, el género o la conciliación con la vida laboral, están ligeramente relacionadas con las repercusiones negativas del cuidado. Asimismo, el trastorno mental cuenta con características o particularidades propias que pueden generar una mayor carga para las cuidadoras que no tienen otras enfermedades, como los síntomas de la enfermedad, el diagnóstico, la incertidumbre o la preocupación por el futuro.

Cabe destacar que en esta investigación, el apoyo social -formal e informal- se posiciona como la variable moderadora de la sobrecarga. El acceso de la persona cuidada a una atención continuada, las terapias psicoeducativas de apoyo y acompañamiento familiar y la participación en movimientos asociativos determinaron los niveles de sobrecarga de las cuidadoras, configurándose como factores de protección ante el impacto negativo del cuidado. De ahí se destacan los beneficios de la creación de espacios de interacción y apoyo y la importancia de la psicoeducación para adquirir competencias en estrategias de afrontamiento y empoderamiento que promuevan relaciones de cuidado satisfactorias. Como señalan Vargas-Huicochea et al. (2018), se debe proporcionar una mejor asistencia a las personas con trastorno mental, implementar intervenciones que brinden apoyo y tratamiento efectivo a las familias, e integrar la atención psicosocial de las cuidadoras como parte de la práctica diaria de los y las profesionales para garantizar el bienestar de estas.

En cuanto al segundo objetivo, los resultados de tercer estudio muestran que España cuenta con un sistema caracterizado por la escasez de recursos financieros y humanos dirigidos a la salud mental, la falta de coordinación efectiva entre todas las instituciones y autoridades involucradas, la carencia de recursos de calidad orientados a la rehabilitación social y recuperación de la persona, la ausencia de un modelo de atención integrada, y la falta de un marco de salud común para todos los y las profesionales. Se destaca el papel consolidado de la familia como recurso esencial y pilar fundamental de la prestación de cuidados y apoyo a largo plazo ante el aumento de la prevalencia de los trastornos mentales y las decisiones gubernamentales que han afianzado un precario sistema de atención.

En este sentido, y en relación con el tercer objetivo del estudio y en complementariedad con los resultados anteriores, la revisión realizada permitió sistematizar las deficiencias y limitaciones de las políticas y procedimientos institucionales que restringen el acceso al tratamiento y la rehabilitación de las personas con trastorno mental, las cuales tienen un impacto directo en las familias, especialmente, en las cuidadoras principales. Esta tesis doctoral proporciona, por tanto, evidencia de la existencia de cinco barreras asociadas al cuidado familiar en salud mental que suponen brechas de las políticas públicas y la intervención profesional, tales como:

- Barreras estructurales que derivan principalmente de la falta de voluntad y compromiso por parte de los gobiernos, y que limitan la creación de legislación específica y la elaboración de presupuestos dirigidos a la prevención, promoción y tratamiento de los trastornos mentales, restringiendo así la planificación, creación de recursos y prestación de servicios.

- Barreras culturales que enmanan de la historia de exclusión y el estigma asociado a la enfermedad mental, las cuales condicionan la búsqueda de ayuda y dan lugar a un desconocimiento generalizado de la enfermedad, promoviendo el uso de prácticas inadecuadas y no científicas o la infrautilización de los servicios.

- Barreras económicas que incluyen un desequilibrio del gasto en salud mental en relación con la carga real de enfermedad, los elevados costos de tratamiento, medicación y hospitalización, así como la privatización de la atención, que genera gastos incalculables en las familias.

- Barreras de tratamiento derivadas de la escasez de profesionales y la falta de recursos comunitarios y de rehabilitación que garanticen la protección de los derechos de las personas con trastorno mental y la recuperación de la vida, conduciendo de nuevo a la institucionalización de la enfermedad mental.

- Barreras vinculadas al mantenimiento y predominio del modelo biomédico en salud mental que contribuye a una vulneración constante, burocratizada y sistemática por parte del sistema, impide la integración real de la salud mental en la atención primaria de la salud, y dificulta la implementación de tratamientos integrados combinados para la persona con trastorno mental y su familia.

Todo ello conduce al uso de la familia como la principal proveedora de cuidados debido a las deficiencias del sistema de salud mental y la ausencia de apoyo formal, asumiendo el cuidado continuo y los costos psicosociales, económicos y laborales que se generan para garantizar su propio bienestar. Esta tesis destaca el familismo no únicamente como valor cultural que comprende el cuidado como una parte natural de la vida familiar, sino como una consecuencia intrínseca de las limitaciones formales de la atención y que está presente en la mayoría de los países del mundo. Los resultados permiten comprobar y reforzar la importancia que merece la familia, como principal agente indiscutible para la provisión de servicios en salud mental.

Esta investigación muestra que estos desafíos son más visibles y alarmantes en países de bajos y medianos ingresos, aunque los modelos de salud mental en HMICs también son ineficientes e inaccesibles. Cabe destacar, que el estigma asociado a la enfermedad mental aparece coetáneo a todas estas barreras y todavía se encuentra duramente establecido en todas las estructuras sociales, posicionándose como el principal factor limitante para la creación y desarrollo de políticas que garanticen el bienestar de este colectivo. Por ello, se considera necesario sensibilizar y formar a la población general y a los y las profesionales de la salud en competencias de alfabetización en salud mental que rompan con los imaginarios sociales adheridos a la enfermedad y que impulsen el conocimiento y la implementación de prácticas que mejoren el reconocimiento, manejo y prevención de los trastornos mentales.

Asimismo, los hallazgos de este estudio muestran que las condiciones sociales de género presentes en la sociedad patriarcal continúan posicionando a la mujer como la figura central encargada de satisfacer las necesidades de todos los miembros y velar por la salud física y mental de toda la familia. En la redacción de estas páginas se ha acuñado el término de cuidadora en femenino, de acuerdo con la percepción profesional y la experiencia de las cuidadoras participantes. A partir de los resultados, se concluye que la feminización del cuidado en salud mental conduce a una doble discriminación, tanto por el estigma asociado a este tipo de trastornos como por su género, forjando dificultades adicionales en el entorno laboral, personal, familiar y sociorrelacional. Por ello, este estudio insta a los organismos e instituciones que trabajan por la igualdad de género a incrementar los recursos públicos dirigidos a la atención de personas con trastorno mental. Esto permitirá aumentar la corresponsabilidad social en este ámbito e impulsar la participación de los hombres en programas relacionados con el cuidado para la asunción de los valores propios de la ética del cuidado desde una óptica de nuevas masculinidades.

En definitiva, el cuidado familiar en salud mental continúa siendo un desafío latente y los sistemas de atención a la salud mental de todo mundo necesitan fortalecerse, especialmente en LMICs. Para ello, es necesario que los sistemas se reformulen a nivel estructural, organizativo y práctico, a través de la reorientación ética y profesional y el desarrollo de un marco global de atención que consolide políticas reales de atención comunitaria, integral e integrada que incluya la participación de personas con trastorno mental y sus familiares. Como señala Davidson (2016), la remodelación del sistema a través de la implementación de prácticas orientadas a la recuperación es un elemento decisivo para la transformación de la sociedad, la comprensión y mejora de la salud mental, y para garantizar el bienestar y la plena inclusión de la persona con trastorno mental y su familia en la comunidad reduciendo la carga de las cuidadoras.

5.2. Implicaciones para el Trabajo Social

Esta tesis doctoral destaca la mirada crítica del Trabajo Social al sistema, incidiendo en la necesidad de que este se transforme y fortalezca, ante la carencia de una planificación estrategica sobre salud mental y la necesidad de configurar una red activa de recursos comunitarios, dotando al sistema de las infraestructuras comunitarias adecuadas y los recursos humanos necesarios para garantizar una atención psicosocial a la salud mental orientada a la recuperación. Se reconoce el papel imprescindible de esta disciplina profesional dentro de los equipos multidisciplinares de atención, configurándose como agente de cambio y transformación de la realidad para brindar una atención integral y terapéutica a usuarios, usuarias y sus familias a través de intervenciones que garanticen su plena inclusión en la comunidad, miminizando las brechas de las políticas públicas y la intervención profesional.

Ante estas precariedades, las familias y, en especial, las cuidadoras deben considerarse como colectivo en riesgo, al encontrarse en situación de vulnerabilidad por la labor que realizan. Por ello, el cuidado familiar debe ser objeto de estudio e intervención desde el Trabajo Social. Los y las profesionales del Trabajo Social en los equipos de salud mental deben posicionarse como las encargadas de brindar apoyo social, potenciar las capacidades y fomentar la participación e involucrar a las personas con trastorno mental y sus familiares en los procesos de tratamiento de la enfermedad. Asimismo, los/as trabajadores sociales deben utilizar programas de psicoeducación familiar para mejorar el bienestar de las cuidadoras.

Desde el ámbito local es necesario motivar y capacitar a los y las trabajadores/as sociales en competencias de salud mental comunitaria para promover la detección precoz de los trastornos mentales, la atención a las cuidadoras y la derivación a recursos específicos e impulsar la gobernanza de salud mental desde la atención primaria de la salud. Asimismo, el Trabajo Social tiene un papel crucial en la sensibilización de otros/as profesionales sobre la importancia de adoptar una visión holística y de recuperación y fortalecer el compromiso para el desarrollo de políticas encaminadas a un mejor y mayor impulso de recursos que aseguren una atención en salud mental de calidad.

Los resultados abogan la necesidad de reorganizar los modelos de organizacionales para ofrecer una atención integrada centrada en la persona con trastorno mental y su familia que permitan la coordinación entre diferentes sistemas e instituciones. Este estudio insta a los y las trabajadores/as sociales a ser el nexo entre atención primaria, salud mental, servicios sociales y recursos comunitarios. No obstante, para garantizar una coordinación y mediación comunitaria efectiva es necesario integrar de manera real la salud mental en todos los ámbitos y aumentar los esfuerzos de liderazgo de la profesión dentro de los equipos de multidisciplinares. El Trabajo Social debe promover acciones profesionales desde las diferentes áreas y campos de intervención que envuelven la salud mental para lograr un impacto social que garantice el reconocimiento social, económico y profesional de las cuidadoras y los cuidados familistas, y la protección de la familia como cuidadora principal de las personas con trastorno mental.

5.3. Fortalezas y Limitaciones de la Investigación

Esta tesis doctoral proporciona datos de carácter novedoso al analizar de una manera crítica e integral las barreras asociadas al cuidado familiar en salud mental a través de un diseño emergente de métodos mixtos. Este diseño ha permitido lograr una perspectiva más amplia del fenómeno a estudio, apoyar con mayor solidez las conclusiones forjadas y optimizar los resultados. Del mismo modo, la combinación de las diferentes metodologías utilizadas ha generado una oportunidad para reforzar las habilidades adquiridas con anterioridad y desarrollar nuevas competencias en materia de investigación.

Este diseño ha permitido alcanzar los resultados desde diferentes perspectivas del problema con muestras representativas de cuidadoras, profesionales y estudios previos. La hetereogeneidad de la procedencia profesional y la amplitud territorial abarcada en el tercer estudio ha posibilitado obtener una visión real y representativa de las brechas de las políticas públicas y la intervención desde la perspectiva profesional. Asimismo, cabe destacar que el cuarto estudio es la primera revisión sistemática sobre esta temática realizada por investigadores e investigadoras no anglosajones publicada en una revista de alto impacto científico.

Además de las limitaciones específicas expuestas en cada estudio, la modalidad escogida para esta tesis doctoral, realizada a través del compendio de publicaciones científicas desde el área de las Ciencias Sociales, también ha supuesto limitaciones adicionales derivadas de los duros y prolongados procesos de selección, presentación, revisión y publicación de las revistas de alto prestigio científico. No obstante, esta modalidad también es una fortaleza, puesto que ha permitido publicar los resultados al mismo tiempo que se realiza la tesis doctoral, ampliando el currículum investigador de la doctoranda, directores y de la propia universidad. Del mismo modo, esta modalidad de tesis ha permitido someter estos resultados a un riguroso control de calidad a través de los procesos de revisión por pares, permitiendo así enriquecer cada estudio y avalar la calidad de esta investigación.

5.4. Líneas de Investigación Futuras

Las barreras de los sistemas de atención a la salud mental configuran una problemática que está muy presente en la sociedad actual y es necesario realizar investigaciones e intervenciones a efectos de mejorar la calidad de vida las cuidadoras para garantizar, a su vez, el bienestar de las personas con trastorno mental. Por ello, este estudio plantea la necesidad de evaluar la eficiencia y la calidad de los sistemas de salud mental y las intervenciones orientadas a la comunidad, utilizando ensayos controlados aleatorios y otros diseños de investigación de alta calidad científica a través del uso de instrumentos estandarizados comunes, como es el Instrumento de Evaluación para Sistemas de Salud Mental propuesto por la WHO (Saymah et al., 2015; WHO, 2005).

En relación con las prioridades de investigación en salud mental y cuidado familiar aclamadas por la literatura científica, este estudio suscita la necesidad de fortalecer la investigación sobre las barreras asociadas al cuidado familiar en la salud mental pero enfocado a niños, niñas y adolescentes, y otros colectivos de riesgo alto riesgo. Asimismo, la importancia del apoyo social como variable moderadora suscita la creación, implementación y evaluación de la eficacia de intervenciones psicoeducativas familiares con el objetivo de formar a las cuidadoras en materia de salud mental y ofrecer apoyo continuo y asesoramiento las cuidadoras para reducir la carga del cuidado. La elevada feminización en el cuidado familiar implica que es necesario abordar todas las investigaciones futuras desde la perspectiva de género y desde una óptica de nuevas masculinidades.

Para finalizar, cabe incidir en el contexto de crisis sanitaria actual. La pandemia de la Covid-19 ha provocado una reestructuración emergente de los modelos sociosanitarios y la aplicación de medidas restrictivas tales como el distanciamiento social o el confinamiento. Los resultados de algunos estudios recientes (Ilmy et al., 2020) sostienen que la carga del cuidado en salud mental está siendo agravada debido a la alteración significativa de las dinámicas familiares, el limitado acceso a recursos de atención continuada, el impacto negativo en la economía familiar o la recurrencia de los síntomas psicóticos. Por ello es necesario realizar estudios que evaluen el impacto de la Covid-19 en la calidad de vida y bienestarde las cuidadoras, además de analizar las implicaciones de la pandemia para la salud mental de la población general y especialmente en colectivos de riesgo.

CHAPTER 5BIS. CONCLUSIONS AND FINAL CONSIDERATIONS

5BIS.1 Conclusions

This doctoral thesis analyses the barriers associated with family care in mental health. The basic aims of the investigation are to explore the factors associated with overload suffered by the family caregivers of people with mental illness, to find out how mental health professionals perceive family caregiving and public policy management in this area, and to analyse the challenges and barriers of mental healthcare systems and the impact they have on the family.

The findings of the four studies set out in the previous chapter indicate that individual caregiver factors are not the only variables that contribute to the burden of family care. There are also a great many contextual factors that are barriers that present challenges to the well-being and quality of life of people who spend much, if not all, of their lives taking care of mental health. The thesis provides a pragmatic and wide-ranging overview of the object of study. Basically it underlines the importance of considering the historical, individual, social, cultural, economic and family context of mental illness as analysed in this investigation when seeking to understand family care in mental health and reduce its negative repercussions.

Previous research into family care in mental health has often analysed the relationship between the sociodemographic and clinical variables of the givers and receivers of care and overload. In pursuit of the first of our aims, the two quantitative studies carried out sequentially in the first stage find high levels of overload among caregivers. The second study shows that individual variables such as age, gender and work-life balance are slightly associated with the negative repercussions of caregiving. In addition, mental illness has its own characteristics that may generate a heavier burden for caregivers than other illnesses. These include symptoms, diagnosis and uncertainty or concern about the future.

It is notable that in this investigation social support, both formal and informal, seems to be the variable that moderates overload. The possibility of the person with mental illness accessing continuous care and psychoeducational support therapies with the family and participating in associations determined the levels of overload among caregivers and acted as a protective factor against the negative impact of caring. Hence the benefits of creating spaces for interaction and support and the importance of psychoeducation in providing competencies in coping and empowerment strategies to foster satisfactory care relationships. As Vargas-Huicochea et al. (2018) observe, better care should be provided for people with mental illness, interventions should be carried out to give effective support and treatment to families, and psychosocial care for caregivers should be an integral part of the day-to-day practices of the professionals in order to guarantee their well-being.

As regards the second aim, the results of the third study show that Spain has a system that is characterized by an insufficient allocation of financial and human resources to mental health, a lack of effective coordination between all the institutions and authorities involved, a dearth of quality resources earmarked for social rehabilitation and recovery, the absence of an integrated healthcare model, and the lack of a common health framework for all professional workers. It is evident that the consolidated role of the family is an essential resource and a basic pillar of long-term caregiving and support, given the increased prevalence of mental disorders and government decisions that have resulted in a precarious healthcare system.

As for the study’s third aim and in complementarity with the above results, carrying out the review made it possible to systematize the deficiencies and limitations of institutional policies and procedures that restrict access to treatment and rehabilitation for people with mental illness and have a direct impact on families, and especially on the main caregivers. This doctoral thesis shows that there are five barriers associated with family caregiving in mental health that point to shortcomings in public policies and professional intervention:

- structural barriers stemming mainly from a lack of willingness and commitment on the part of the government that limit the creation of specific legislation and the drawing-up of budgets aimed at preventing, promoting and treating mental illness, thereby restricting planning, the creation of resources and the provision of services.

- cultural barriers that have their origins in past exclusion and the stigma attached to mental illness, which condition the search for help and give rise to a widespread lack of knowledge of the illness, leading to the spread of unsuitable, unscientific practices or the underuse of services.

- economic barriers that include an imbalance in spending on mental health in relation to the real illness burden, the high cost of treatment, medication and hospitalization, plus the privatization of healthcare, which generates incalculable costs for families.

- treatment barriers deriving from a shortage of professional workers and insufficient community and rehabilitation resources to guarantee the rights of people with mental illness and their return to a meaningful and productive life, leading again to the institutionalization of mental illness.

- barriers associated with the maintenance and predominance of the biomedical model in mental health, which contributes to a constant, systematic and bureaucratic interference on the part of the system, impedes the real integration of mental health into primary healthcare and makes it difficult to implement combined integrated treatments for the person with mental illness and their family.

The result of all this is that the family is used as the main care provider due to deficiencies in the mental healthcare system and the absence of formal support, and has to take on the responsibility of continuous care along with the psychosocial, economic and labour costs that this entails in order to guarantee its own well-being. This thesis underlines the fact that familism is not simply a cultural value that includes caregiving as a natural part of family life, but is an intrinsic consequence of the formal limitations of healthcare that is present in most countries of the world. The results enable us to confirm and stress the importance of the family as the undeniable main agent in the provision of mental health services.

This investigation shows that these challenges are more visible and more alarming in low- and middle-income countries, although mental healthcare models in HMICs are also inefficient and difficult to access. The stigma associated with mental illness seems to be part and parcel of all these barriers and is still firmly rooted in all social structures, acting as the main limiting factor to the creation and development of policies to guarantee the well-being of this collective. The general population and health professionals should therefore be educated and trained in the competencies of mental health literacy to break away from the image that society has of the illness and to foster knowledge and the use of practices aimed at improving the recognition, handling and prevention of mental disorders.

The findings of this study also show that the social conditions of gender that are present in the patriarchal society continue to place women as the central figures responsible for satisying the needs of all its members and for looking after the physical and mental health of the whole family. In the writing of these pages in the original Spanish the term *cuidadora* (caregiver) in the feminine form was used, which is in line with the professional perception and experience of the caregivers that participated. It can be concluded from these results that the feminization of mental healthcare leads to a twofold discrimination due to both the stigma associated with this type of illness and the caregivers' gender, and this gives rise to additional problems in the labour, personal, family and sociorelational spheres. The study therefore urges those organizations and institutions that work in the field of gender equality to increase the public resources allocated to caring for people with mental illness. This would make it possible to increase social co-responsibility in this area and encourage men to participate in programmes focusing on caring so that they can assume the moral values characteristic of caring from the perspective of new masculinities.

In short, family care in mental health continues to be a latent challenge and mental healthcare systems all over the world need to be strengthened, especially in LMICs. In order for this to happen, they need to be redesigned at a structural, organizational and practical level according to an ethical and professional reorientation. A global care framework should be established to consolidate real community healthcare policies that are both comprehensive and integrated and include the participation of people with mental illness and their families. As Davidson (2016) points out, redesigning the system by implementing practices aimed at recovery is a crucial element for the transformation of society, for understanding and improving mental health, and for guaranteeing the well-being and full inclusion of the person with mental illness and their family in the community, thereby reducing caregiver burden.

5BIS.2 Implications for social work

This doctoral thesis emphasizes social work's critical view of the system, underlining the need for it to be transformed and strengthened given the lack of strategic planning for mental health. There is also a need to set up an active network of community resources to provide the system with the appropriate community infrastructures and the necessary human resources to guarantee psychosocial mental healthcare aimed at recovery. It is recognized that social work plays a crucial role in multidisciplinary healthcare teams, acting as an agent of change and transformation of the reality in order to give users and their families comprehensive therapeutic care and, through interventions, to guarantee their full inclusion in the community, thus minimizing the shortcomings of public policies and professional intervention.

Given these shortcomings, families – and especially caregivers – should be considered an at-risk group, since they are in a vulnerable situation because of the tasks they carry out. Family caregiving should therefore be an object of study and intervention on the part of social work. Social work professionals in mental health teams should be in a position to take responsibility for providing social support, boosting capabilities and encouraging the participation and involvement of people with mental illness and their families in the illness treatment processes. They should also make use of family psychoeducation programmes to improve the well-being of the caregivers.

At a local level, social workers need to be motivated and trained in community mental health competencies so they can deal with the early detection of mental disorders, caregiver care, referrals to specific resources and the promotion of mental health governance from the primary healthcare area. Social work also has a crucial role to play in making other professionals aware of the importance of adopting a holistic, recovery-oriented view and strengthening commitment to the development of policies aimed at boosting the resources needed to ensure quality mental healthcare.

The results point to the need to redesign organizational models in order to provide integrated care focusing on the person with mental illness and their family so as to enable coordination between different systems and institutions. This study urges that social workers should be the link between primary healthcare, mental health, social services and community resources. However, in order to guarantee effective community coordination and mediation, mental health needs to be truly integrated in all areas and the profession's leadership within the multidisciplinary teams need to be strengthened. Social work must foster professional actions from the various different areas and fields of intervention involved in mental health so as to achieve a social impact that guarantees not only the social, economic and professional recognition of familist caregivers and caregiving, but also the protection of the family as the main caregiver for people with mental illness.

5BIS.3 Strengths and limitations of the research

This doctoral thesis supplies new data through the critical and comprehensive analysis of the barriers associated with family care in mental health using an emergent mixed methods approach. This has made it possible to achieve a wider view of the subject under study, provide more solid support for the conclusions and optimize the results. The combination of different methodologies has also provided an opportunity to strengthen previously acquired skills and to develop new abilities in the field of research.

Such an approach has made it possible to reach results from different perspectives of the problem using representative samples of caregivers and professionals and the review of previous studies. The heterogeneity of the professionals' areas of origin and the territory covered in the third study has allowed us to obtain a real and representative view of the shortcomings in public policies and intervention from a professional perspective. It should also be pointed out that the fourth study is the first systematic review of this subject carried out by non-Anglo-Saxon researchers and published in a high-impact scientific journal.

Apart from the specific limitations mentioned in each separate study, the format chosen for this doctoral thesis – a compendium of scientific publications in the area of social sciences – has also meant additional limitations deriving from the lengthy selection, presentation, review and publication processes used by prestigious scientific journals. However, this format has also been a strength insofar as the results were able to be published at the same time as the doctoral thesis was being produced, adding to the research track record of the doctoral candidate, the thesis directors and the university itself. It also means that the results have undergone rigorous quality control in the shape of peer-review processes, thereby enriching each study and endorsing the quality of the investigation.

5BIS.4 Future lines of research

The barriers in the mental healthcare system give rise to a problem frequently seen in today's society, and investigations and interventions need to be carried out in order to improve the caregivers' quality of life while at the same time guaranteeing the well-being of people with mental illness. This study therefore suggests that there is a need to assess the effectiveness and quality of mental healthcare systems and interventions aimed at the community through random controlled trials and other high-quality scientific research designs using common standardized instruments such as the WHO's Assessment Instrument for Mental Health Systems (Saymah et al., 2015; WHO, 2005).

As regards the priorities for research into mental health and family care espoused by the scientific literature, this study points to the need to increase research into the barriers associated with family care in mental health but with the focus on children and adolescents and other high-risk groups. In addition, the importance of social support as a moderating variable calls for the creation, implementation and evaluation of the effectiveness of psychoeducational family interventions with the aim of training caregivers in mental health matters and providing continuous support and assessment to caregivers in order to reduce the care burden. The high level of feminization in family care means that all future research should be approached from a gender perspective and from the point of view of new masculinities.

Finally, the context of the current health crisis should be borne in mind. The COVID-19 pandemic has brought about an emergent restructuring of public health models and the application of restrictive measures such as social distancing and lockdown. The results of some recent studies (Ilmy et al., 2020) indicate that the mental health care burden is being aggravated by the significant change in family dynamics, the limited access to continuous care resources, the negative impact on the family economy and the recurrence of psychotic symptoms. Studies therefore need to be carried out to assess the impact of COVID-19 on the quality of life and well-being of caregivers and to analyse the implications of the pandemic for the mental health of the general population and especially at-risk groups.

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CAPÍTULO 7. ANEXOS

ANEXO 7.1. Índice de Tablas y Figuras

Tablas

Figuras

ANEXO 7.2. Listado de Acrónimos

Acrónimos	
CASP	Critical Appraisal Skills Programme
CCRBT	Cochrane Collaboration Risk of Bias Tool
EUFAMI	European Federation of Associations of Families of People with Mental Illness
FEAFES	Confederación Española de Agrupaciones de Familiares y Personas con Enfermedad Mental
FG	Focus group
HICs	High and upper-middle income countries
JCR	Journal Citation Reports
LMICs	Low- and middle-income countries
MGMH	Movement for Global Mental Health
mhGAP	Mental Health Gap Action Programme
NAMI	National Alliance on Mental Illness
ODM	Objetivos de Desarrollo del Milenio
PRISMA-P	Preferred Reporting Items for Systematic review and Meta-Analysis Protocols
SDGs	Sustainable Development Goals
SJR	SCImago Journal Rank
SMD	Serious Mental Disorders
SMI	Several Mental Illness
WHO	World Health Organization
WHO-AIMS	WHO’s Assessment Instrument for Mental Health Systems

ANEXO 7.3. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			

Topic	**Item No.**	**Guide Questions/Description**	**Reported on Page No.**
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: 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. http://doi.org/0.1093/intqhc/mzm042

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

ANEXO 7.4. PRISMA-P 2015 Checklist: Recommended Items to Include in a Systematic Review Protocol[a]

Section/topic	Item #	Checklist item
ADMINISTRATIVE INFORMATION		
Title		
Identification	1a	Identify the report as a protocol of a systematic review
Update	1b	If the protocol is for an update of a previous systematic review, identify as such
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number
Authors		
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments
Support		
Sources	5a	Indicate sources of financial or other support for the review
Sponsor	5b	Provide name for the review funder and/or sponsor
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol
INTRODUCTION		
Rationale	6	Describe the rationale for the review in the context of what is already known

Section/topic	Item #	Checklist item
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)
METHODS		
Eligibility criteria	8	Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review
Information sources	9	Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated
Study records		
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review
Selection process	11b	State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis)
Data collection process	11c	Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators
Data items	12	List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis

Section/topic	Item #	Checklist item
Data		
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., I^2, Kendall's tau)
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)

PRISMA-P Preferred Reporting Items for Systematic review and Meta-Analysis Protocols.

Developed from: Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., … Stewart, L. A. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, *4*(1), 1–9. https://doi.org/10.1186/2046-4053-4-1

[a] It is strongly recommended that this checklist be read in conjunction with the PRISMA-P Explanation and Elaboration (Shamseer et al., 2015) for important clarification on the items. Amendments to a review protocol should be tracked and dated. The copyright for PRISMA-P (including checklist) is held by the PRISMA-P Group and is distributed under a Creative Commons Attribution License 4.0.

ANEXO 7.5. Pontuação para Autoria, de acordo com a Participação no Trabalho

Participação	Pontos
Criar a idéia que originou o trabalho e elaborar hipóteses	6
Estruturar o método de trabalho	6
Orientar ou coordenar o trabalho	5
Escreveromanuscrito	5
Coordenar o grupo que realizou o trabalho	4
Rever a literatura	4
Apresentar sugestões importantes incorporadas ao trabalho	4
Resolver problemas fundamentais do trabalho	4
Criar aparelhos para a realização do trabalho	3
Coletardados	3
Analisar os resultados estatisticamente	3
Orientar a redação do manuscrito	3
Preparar a apresentação do trabalho para evento científico	3
Apresentar o trabalho em evento científico	2
Chefiar o local onde o trabalho foi realizado	2
Fornecer pacientes ou material para o trabalho	2
Conseguir verbas para a realização do trabalho	2
Apresentarsugestões menoresincorporadas ao trabalho	1
Trabalhar na rotina da função, sem contribuição intelectual	1
Participar mediante pagamento específico	5

* Terão direito a autoria os colaboradores que tiverem alcançado 7 pontos.

A seqüência dos autores será em ordem decrescente de pontuação.

Desenvolvido por: Petroianu, A. (2002). Autoria de um trabalho científico. *Revista da Associação Médica Brasileira, 48*(1), 60-65. https://doi.org/10.1590/S0104-42302002000100034

ANEXO 7.6. Artículo 1. Family burden, social support, and community health in caregivers of people with serious mental disorder

REVISTA DA ESCOLA DE ENFERMAGEM DA USP
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Family burden, social support and community health in caregivers of people with serious mental disorder*

Sobrecarga familiar, apoyo social y salud comunitaria en cuidadores de personas con trastorno mental grave

Sobrecarga familiar, apoio social e saúde comunitária em cuidadores de pessoas com transtorno mental grave

José Javier Navarro Pérez[1], Ángela Carbonell Marqués[1]

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[*] Extracted from the thesis: "Factores asociados al cuidado familiar de una persona con Trastorno Mental Grave", Universidad de Valencia, 2016.

[1] Universidad de Valencia, Facultad de Ciencias Sociales, Departamento de Trabajo Social y Servicios Sociales, Valencia, Spain.

ABSTRACT

Objective: To identify caregivers' level of burden and analyze the factors associated with family care in mental health. **Method:** A cross-sectional descriptive study was conducted between January and July 2016. A sample of caregivers from seven public institutions and an association of relatives and patients was evaluated by identifying their burden and the contributing factors for reduction of these levels through the Zarit Burden Inventory instrument. The study was conducted according to recommendations of the ethics committees of the participating institutions. **Results:** Participation of 107 caregivers. The main contributions refer that caregivers' active participation in associative dynamics, their attendance at psychoeducational activities and territorial connection to metropolitan areas with community resources decrease their level of burden. **Conclusion:** Community nursing is highly important and responsible for preventing levels of burden and increasing health levels. In addition, many proposals are formulated in order to favor social support networks by combining treatments and increasing public health programs in contact with the community.

DESCRIPTORS

Mental Disorders; Caregivers; Family; Social Support; Community Health Nursing.

Corresponding author:
Ángela Carbonell Marqués
Facultad de Ciencias Sociales,
Universidad de Valencia
Avenida dels Tarongers, 4b, Despacho 1D19
46022 – Valencia, Spain
angela.carbonell@uv.es

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INTRODUCTION

Serious mental disorders (SMD) involve several psychiatric diagnoses of prolonged duration, which result in a high degree of physical, mental and social disability that reduces the quality of life of affected individuals and their family(1). Authors(2) describe this type of illness as one of the predictors of risk of dependency, because it causes significant loss of autonomy and demands constant attention and assistance from another person for performing basic and instrumental activities of daily life. In many cases, this is the reason for the constant need for attention and support required by this group of people, since the illness causes disability. Together with the lack of resources, that fact means the care of people with a serious mental disorder falls fundamentally in the hands of relatives, who place themselves as caregivers and responsible for the well-being of family members(3). In general, this care becomes responsibility of a single member of the family who, almost exclusively, is a woman.

Family caregivers' main function is helping to meet the dependent person's basic and instrumental needs of daily life(4). The main caregivers are exposed to various challenges and stressors on a daily basis, which make them feel loss of personal control, resulting in physical and emotional alterations that can lead to the 'Caregiver syndrome'(5), and confrontation of a wide variety of risk factors that undermine their well-being. In addition, this pathology integrates a series of negative personal and work factors affecting informal caregivers' well-being, and giving rise to feelings of emotional exhaustion, depersonalization and even lack of personal fulfillment outside family care. This can be motivated by the loss of work and job opportunities experienced by people devoting most of their time to the care of a family member, which worsens the economic situation because of direct costs and decreased family productivity(6). The consequences of caregivers' great investment of time are less leisure and social relations, the projection of frailties around them, and vulnerability in situations of isolation and social exclusion(7).

The care of people diagnosed with a serious mental disorder presupposes significant economic, mental and personal exhaustion of those responsible for their daily care(8). The scientific literature emphasizes that caring for people with serious mental disorders is a heavier burden than caring for people with other types of diseases(9). Some factors influencing this deterioration are the burden of caring for a sick person, lack of specific training for the provision of adequate care, and the preparation to face the intrinsic situations to that same care(10). All these aspects together with the stigma and social rejection of the illness itself and its association with violence, support the false social belief that people suffering from SMD are aggressive because of the disease nature, hence this is considered a risk factor for the care. This issue is aggravated by the way it affects interpersonal relationships, the lack of balance between the illness cost and the belief that violent behaviors arise as a demonstration of disappointment, stigma and rejection towards the disorder itself(11).

Different authors have tried to evaluate the impact of sociodemographic and clinical variables both of people with serious mental disorders and their caregivers, and of the burden. The results of these studies associate a higher level of burden based on variables such as sex, kinship, having a paid job, the type of mental disorder, etc. On the other hand, these authors correlate positively the caregiver's age, years of disease evolution, number of hospital admissions and the degree of disability and dependency as variables associated with the main caregiver's burden(12-13). Likewise, social support is a protective factor to face care situations because it positively affects caregivers' psychological well-being and quality of life. According to these studies, caregivers experience greater burden when the perceived social support is lower(14-16).

The models of care for dependent individuals have changed over time in order to adapt to the needs and respond to this group's psychic and psychosocial problems. In Spain, the social care model for dependent individuals has favored their maintenance in the family and social context, which makes families the main support and care axis. Nursing is an area responsible for providing health education and care in the best possible conditions, not only to sick people, but also to their caregivers by assessing the possible effects of this work on them(17). In this sense, community nursing is key in the process of psychophysical rehabilitation, support and social integration of people with illnesses and their caregivers(18).

Thus, the need to investigate the situation of people who dedicate their lives to the care of another person(19-20). Therefore, the objective of the present study has two aspects; on the one hand, to identify caregivers' level of burden, and on the other, to analyze the factors associated with family care in mental health.

METHOD

TYPE OF STUDY

A cross-sectional descriptive study was performed by using the survey data collection technique. The study period was between the months of January and July 2016 in seven mental health care institutions in the province of Valencia and in an association of relatives and patients.

PARTICIPANTS

The sample included 107 caregivers who met the following inclusion criteria: caregivers of people with SMD included in the public system of Mental Health care in the Valencian Community; residence in the province of Valencia; presence of kinship ties with the sick person; age over 18 years old; performance of the primary caregiver role by adopting functions of care and supervision in basic and/or instrumental activities of daily life of the person with mental health problems; absence of remuneration for the work they do; performance of care for more than six months.

Exclusion criteria were to reject participation in the study, caregivers of people with diagnoses not classified as serious mental disorders (intellectual disability, behavioral or psychomotor development alterations) or for not being correctly completed.

INSTRUMENTS

The chosen scale(21), the Zarit Burden Inventory/Zarit Test(22-23) was selected as the data collection instrument given the extensive scientific literature demonstrating its use and validity. The aim of this instrument is the assessment of the level of burden experienced by caregivers of people with dementia. However, it has also been used for caregivers of people with mental illness because of the similar chronicity of both groups(24-25). The present study obtained a Cronbach's alpha coefficient of 0.92 for the scale.

In order to analyze the sociodemographic characteristics of caregivers and identify their relationship with the level of burden, the most present sociodemographic and clinical variables in the scientific literature and that according to authors were collected, which are related to the Caregiver syndrome, namely: 1) Variables describing the caregiver: age, sex, marital status, kinship with the sick person, having paid work, presence of chronic illness, active associationism, attendance at family psychoeducational talks and workshops, geographical environment and type of care received; and 2) Variables describing the person with SMD: age, sex, diagnosed illness, years of evolution of the disease, recognized degree of disability, and Mental Health care service they use.

PROCEDURE

Considering the Spanish Mental Health care system does not attend caregivers directly, data collection was performed in seven institutions of the public Mental Health care system in the Valencian Community, province of Valencia, and in an association of relatives and patients. The community nurses used the appointments attended by users with a family member for identifying, from their professional judgment, those who performed the role of main caregiver of the person served.

An individualized interview was arranged with each study participant. Assessments were performed by community nurses with training in application of instruments. When a high level of burden was detected, the interviewee was informed about the existence of psychoeducational programs for relatives.

This study was conducted in accordance with recommendations of the ethics committees of participating institutions and met the national (Law 14/2007, of July 3 of biomedical research) and international standards of ethics in research. The results of the present study are taken from a broader study approved by the Commission of Ethics and Experimental Research of the Faculty of Social Sciences of the Universidad de Valencia under reference number 000217/UV-Soc/2016. Subjects who met the inclusion criteria for this study received prior information and gave their written consent for voluntary participation according to the Declaration of Helsinki (2013). Participants were explained about the possibility of interrupting or withdrawing their participation at any time.

DATA ANALYSIS

For the quantitative analysis, firstly, was performed a descriptive study of data for identifying the characteristics of the caregiver and the person cared for based on sociodemographic and clinical variables. Then, it was identified the relationship between the variables defining the caregiver and the person cared for, and the burden. Contingency tables and chi-square tests were used to verify statistically significant differences between the burden and nominal variables. A correlation analysis was performed in order to demonstrate the existence of a linear relationship between the level of burden and quantitative variables. Finally, a linear regression with the variables that had a significant relationship with the level of burden in previous analyzes was performed in order to define a predictive model of burden. Nominal variables were recoded as Dummy variables (fictitious) so they could be incorporated into the regression model. The data analysis process was performed with use of the IBM SPSS Statistics 25 software. For all tests, $p<0.5$ was considered as the level of statistical significance.

RESULTS

CAREGIVERS' CHARACTERISTICS

The total sample of the study included 107 family caregivers of people with Serious Mental Disorder treated in seven public mental health care services and an association of relatives and patients (Table 1). Women represented 71% of the sample, and 29% were men, age was between 16 and 89 years old (M=60.67; SD=13.83). Regarding marital status, 51.4% were married, 15% were divorced, 21.5% were widowed and 12.1% were single. Among interviewees, 41.1% had a paid job, and the same percentage claimed to have a chronic disease. Most caregivers were fathers/mothers of the person with SMD (78.5%), 12.1% were siblings, 4.5% were children, 3.7% were spouses and 0.9% were uncles/aunts. Of caregivers participating in the study, 48.6% had previously assumed the care of another person. This same percentage had attended psychoeducational talks for relatives in Mental Health services and 15% participated in associative activities for relatives and people with SMD.

The subjects diagnosed with chronic mental disorders were mostly male (72.4%), aged 38.64 years (SD=12.63) on average (ranging between 16 and 80 years). All were diagnosed with some Serious Mental Disorder, and the following stood out: schizophrenia (63.6%), bipolar disorder (15.9%), personality disorders (10.3%), dysthymia and chronic depression (4.7%). Obsessive compulsive disorder and schizophrenia, dual pathology and schizoaffective disorder appeared in lower percentages with 1.9% each. Of these people, 50.5% had a Recognition of the Degree of Disability of 65% or higher, while 19.6% did not have it recognized or had not requested it. The mean number of years of evolution of the disease was 17.28 (SD=13.18) and ranged between three months and 56 years.

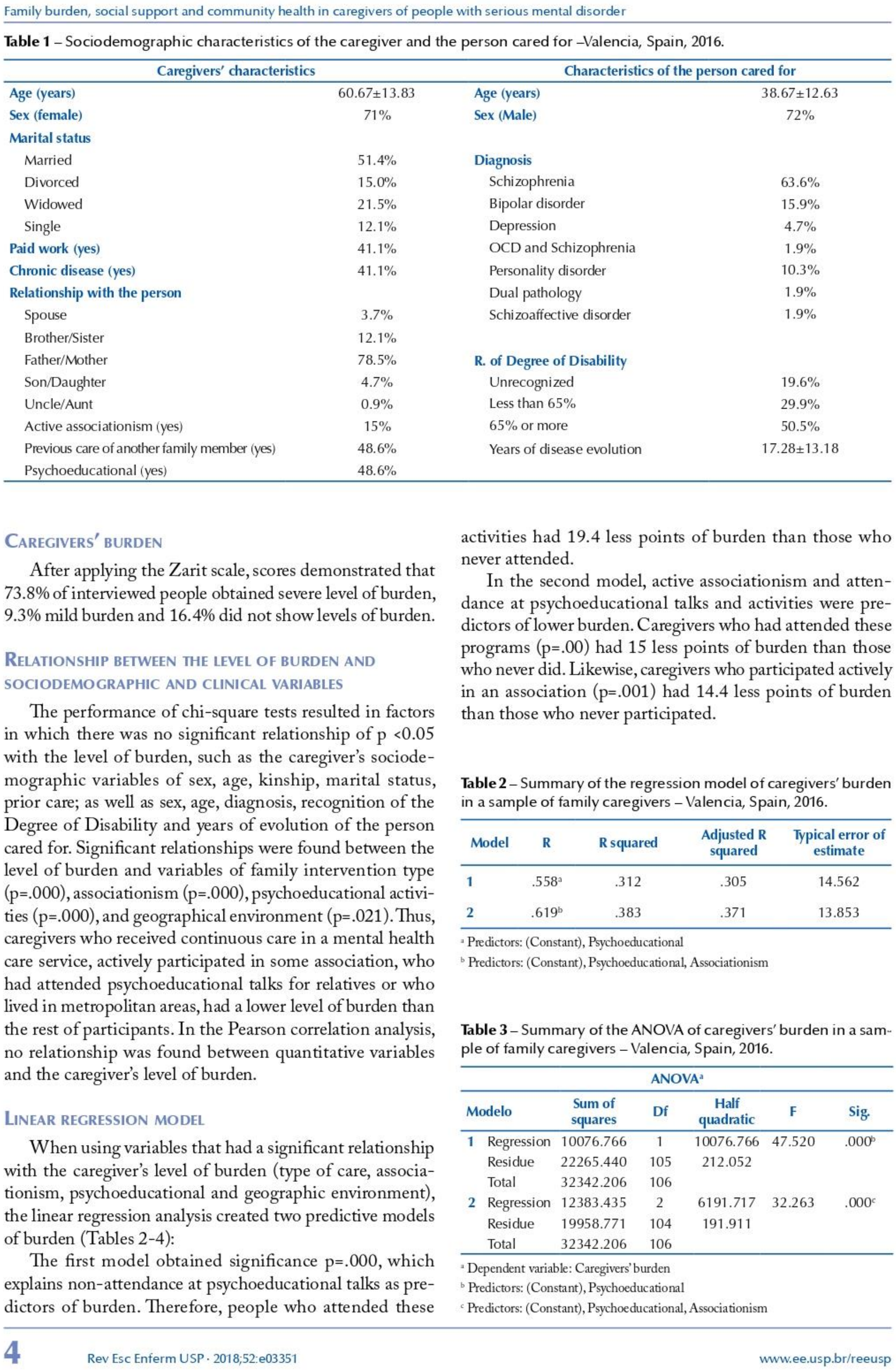

Table 1 – Sociodemographic characteristics of the caregiver and the person cared for –Valencia, Spain, 2016.

Caregivers' characteristics		Characteristics of the person cared for	
Age (years)	60.67±13.83	**Age (years)**	38.67±12.63
Sex (female)	71%	**Sex (Male)**	72%
Marital status			
Married	51.4%	**Diagnosis**	
Divorced	15.0%	Schizophrenia	63.6%
Widowed	21.5%	Bipolar disorder	15.9%
Single	12.1%	Depression	4.7%
Paid work (yes)	41.1%	OCD and Schizophrenia	1.9%
Chronic disease (yes)	41.1%	Personality disorder	10.3%
Relationship with the person		Dual pathology	1.9%
Spouse	3.7%	Schizoaffective disorder	1.9%
Brother/Sister	12.1%		
Father/Mother	78.5%	**R. of Degree of Disability**	
Son/Daughter	4.7%	Unrecognized	19.6%
Uncle/Aunt	0.9%	Less than 65%	29.9%
Active associationism (yes)	15%	65% or more	50.5%
Previous care of another family member (yes)	48.6%	Years of disease evolution	17.28±13.18
Psychoeducational (yes)	48.6%		

CAREGIVERS' BURDEN

After applying the Zarit scale, scores demonstrated that 73.8% of interviewed people obtained severe level of burden, 9.3% mild burden and 16.4% did not show levels of burden.

RELATIONSHIP BETWEEN THE LEVEL OF BURDEN AND SOCIODEMOGRAPHIC AND CLINICAL VARIABLES

The performance of chi-square tests resulted in factors in which there was no significant relationship of p <0.05 with the level of burden, such as the caregiver's sociodemographic variables of sex, age, kinship, marital status, prior care; as well as sex, age, diagnosis, recognition of the Degree of Disability and years of evolution of the person cared for. Significant relationships were found between the level of burden and variables of family intervention type (p=.000), associationism (p=.000), psychoeducational activities (p=.000), and geographical environment (p=.021). Thus, caregivers who received continuous care in a mental health care service, actively participated in some association, who had attended psychoeducational talks for relatives or who lived in metropolitan areas, had a lower level of burden than the rest of participants. In the Pearson correlation analysis, no relationship was found between quantitative variables and the caregiver's level of burden.

LINEAR REGRESSION MODEL

When using variables that had a significant relationship with the caregiver's level of burden (type of care, associationism, psychoeducational and geographic environment), the linear regression analysis created two predictive models of burden (Tables 2-4):

The first model obtained significance p=.000, which explains non-attendance at psychoeducational talks as predictors of burden. Therefore, people who attended these activities had 19.4 less points of burden than those who never attended.

In the second model, active associationism and attendance at psychoeducational talks and activities were predictors of lower burden. Caregivers who had attended these programs (p=.00) had 15 less points of burden than those who never did. Likewise, caregivers who participated actively in an association (p=.001) had 14.4 less points of burden than those who never participated.

Table 2 – Summary of the regression model of caregivers' burden in a sample of family caregivers – Valencia, Spain, 2016.

Model	R	R squared	Adjusted R squared	Typical error of estimate
1	.558[a]	.312	.305	14.562
2	.619[b]	.383	.371	13.853

[a] Predictors: (Constant), Psychoeducational
[b] Predictors: (Constant), Psychoeducational, Associationism

Table 3 – Summary of the ANOVA of caregivers' burden in a sample of family caregivers – Valencia, Spain, 2016.

ANOVA[a]						
Modelo		Sum of squares	Df	Half quadratic	F	Sig.
1	Regression	10076.766	1	10076.766	47.520	.000[b]
	Residue	22265.440	105	212.052		
	Total	32342.206	106			
2	Regression	12383.435	2	6191.717	32.263	.000[c]
	Residue	19958.771	104	191.911		
	Total	32342.206	106			

[a] Dependent variable: Caregivers' burden
[b] Predictors: (Constant), Psychoeducational
[c] Predictors: (Constant), Psychoeducational, Associationism

Table 4 – Regression coefficients of caregivers' burden in a sample of family caregivers – Valencia, Spain, 2016.

Modelo		Unstandardized coefficients		Standardized coefficients	t	Sig.
		B	Typ. error	Beta	B	Typ. error
1	(Constant)	75,782	1,964		38,594	,000
	Psychoeducational	-19,416	2,817	-,558	-6,893	,000
2	(Constant)	75,782	1,868		40,569	,000
	Psychoeducational	-14,976	2,970	-,431	-5,043	,000
	Associationism	-14,431	4,162	-,296	-3,467	,001

^{a} Dependent variable: Caregivers' burden

In accordance with the second model obtained in the linear regression, the burden of the caregiver of a person with Serious Mental Disorder would be represented by the following:

$$Y^{1} = B_{0} + B_{1}X1 + B_{2}X_{2}$$

BURDEN = 75.78 + (-14.976) Psychoeducational + (-14.431) Associationism

DISCUSSION

Serious mental disorders cause effects on biological, psychological and social spheres of people affected by these illnesses, which makes them a susceptible population for receiving long-term care and assistance(1-2). Studies refer that people who care for another with a serious mental disorder have high levels of burden, which leads to a series of psychological, physical, economic and social factors that negatively affect the caregiver(8). The present study identified variables associated with the burden perception of family caregivers of people with serious mental disorders.

The predominant profile is that of a woman, average age of 60 years, married, usually the mother of the person with mental disorder and who does not have a paid job. The present study shows the high feminization as one of the main characteristics defining formal and informal care, since 71% of people performing the care were women, which is in line with authors(2,19), and demonstrates how evident and necessary is an approach from the gender perspective in informal care.

The scientific literature defends the relationship between the sociodemographic variables of the caregiver and the person cared for and the illness characteristics with the level of burden and risk factors. The most prominent variables in the studies were the following: age, sex, professional occupation and educational level of the caregiver; as well as kinship, age, years of evolution of the illness and severity of symptoms of the person cared for(12-13). However, given the high levels of burden found in most subjects under study, the statistical tests performed for quantitative data analysis indicate that in this sample, the burden had no significant relationship with any of these variables, as it depends on the social support (formal and informal) received by the caregiver.

Different studies(14-16) emphasize the importance of social support as a variable that moderates the negative impact of performing the caregiver's role, as a stress shock absorber. In the present study, professionals' access to continuous care, active associationism and attendance at psychoeducational talks and workshops for relatives determined caregivers' levels of burden. Likewise, and coinciding with those authors, these last two variables enabled the definition of a predictive model of burden in which people with higher social support showed lower levels of burden due to the care they perform.

Recent studies emphasized the high impact of the family as a channel of access to socialization(26). This dimension favors the coping of members of the family nucleus(27) by highlighting among these, the social support provided by parents and the potential generated from the network of relationships. Our results address this issue, as social support possibilities were built from the immersion of both relatives and patients in community activities. We agree with other analyses(28) that confirm the importance of a stable affectivity in everyday family relationships as a key factor for social adjustment and reduction of emotional burden.

Studies(29) state that the lack of social support in stressful situations affects the stability of people in need of help and consequently, of those around them or with whom they live, and related the parents' commitment to psychoeducational activities with lower levels of stress. These data are in line with our results, since relatives who attended support activities for the illness, felt less burden.

In parallel, metropolitan areas have greater and better possibilities of integration for people with SMD and their relatives given the wider and diversified offer. Our results were close to those of other authors, because in rural areas or those with less supply, the level of burden and even mortality was higher compared to large cities or those with greater prosocial leisure opportunities, diversified offer or recreational areas. The community is highly important for the collective development and welfare, therefore, the creation of social support networks improves the quality of life and mental health of its members(30).

Nursing faces the challenge and opportunity of making care significant and a priority for mental health by ensuring continuity of care and formal support that can answer sensitively and effectively to the needs of subjects and their caregivers(17-18).

CONCLUSION

Serious mental disorders are considered a public health problem worldwide that mainly affects the quality of life of people who suffer from it and their families. People with serious mental disorders sometimes require assistance and support for the performance of daily tasks. The person who assumes the caregiver role has a number of risk factors associated with the burden arising from this work. For this reason, informal caregivers are a group at risk, because they find themselves in situations of vulnerability, isolation and, in certain cases, exclusion.

In the present study, were found limitations in relation to procedures of participant selection and final sampling. Community Nursing professionals were chosen because they are in regular contact with patients and their caregivers, objects of empirical study. Sampling was based on three filters, namely: companions of people attended at institutions that fulfilled the aforementioned inclusion criteria, who performed (according to professional judgment) the caregiver role, and agreed voluntarily to participate in the study. Two problems emerged from this selection: 1) the sample of caregivers was selected subjectively and based on discretion of the professional who provided the questionnaires, y 2) questionnaires were provided only for those who accompanied the diagnosed person to the institution, which prevented access to a larger sample.

However, the findings of this study highlight the benefits of creating associative spaces of community interaction and mutual support, and the importance of psychoeducational workshops in order to understand the illness processes, develop coping strategies and empower caregivers and the people cared for.

Therefore, public health authorities should focus their efforts on the social welfare of the population they serve. In this sense, it would be advisable to support the following proposals: Encourage coordinated support networks between the areas of health education, nursing and community services, and increase mental health programs in the community by jointly favoring combined treatments for the recovery and stability of people with SMD hence, releasing the burden of caregivers. The present study mentions the need to promote community-based day hospitals where users can go in order to receive health treatment and expand their social circuit; collaborate from the health administration in the creation of associations of relatives of people with SMD, of users, or mixed associations in order to boost the support networks available and generate new ones, and implement complementary programs to those articulated with public health; and connect rural areas or those of scarce resources with metropolitan geographic areas for the reduction of family burden levels of caregivers and for the recovery and psychiatric stabilization of people with illnesses.

Ultimately, the associationism, social support programs in the community and rehabilitative socio-health activities are protective factors, and the lack of structure for their development can generate risk practices for both caregivers and people with illnesses, and have impact on community deterioration.

RESUMEN

Objetivo: Identificar el nivel de sobrecarga de los cuidadores y analizar los factores asociados con el cuidado familiar en salud mental. **Método:** Se realizó un estudio descriptivo transversal realizado entre los meses de enero y julio del año 2016, en el que se evalúa una muestra de cuidadores de siete dispositivos públicos y una asociación de familiares y pacientes identificando la sobrecarga de los mismos y los factores que contribuyen a reducir estos niveles, a través del instrumento *Zarit Burden Inventory*. El estudio se llevó a cabo de acuerdo a las recomendaciones de los comités de ética de las instituciones participantes. **Resultados:** Participaron 107 cuidadores. Las principales aportaciones refieren que la participación activa del cuidador en dinámicas asociativas, la asistencia a actividades psicoeducativas y la vinculación territorial a áreas metropolitanas con recursos comunitarios, disminuyen el nivel de sobrecarga del cuidador. **Conclusión:** Finalmente, destaca la importancia y responsabilidad de la enfermería comunitaria a efectos de prevenir los niveles de sobrecarga e incrementar los de salud; además, se realizan una serie de propuestas en la línea de favorecer redes de apoyo social, combinar tratamientos e incrementar los programas de salud pública en contacto con la comunidad.

DESCRIPTORES

Trastornos Mentales; Cuidadores; Familia, Apoyo Social; Enfermería en Salud Comunitaria.

RESUMO

Objetivo: Identificar o nível de sobrecarga dos cuidadores e analisar os fatores associados ao cuidado familiar em saúde mental. **Método:** Foi realizado um estudo descritivo transversal entre os meses de janeiro e julho do ano 2016, no qual foi avaliada uma amostra de cuidadores de sete dispositivos públicos e uma associação de familiares e pacientes identificando a sobrecarga dos mesmos e os fatores que contribuem para reduzir esses níveis, por meio do instrumento *Zarit Burden Inventory*. O estudo foi realizado de acordo com as recomendações dos comitês de ética das instituições participantes. **Resultados:** Participaram 107 cuidadores. As principais contribuições relatam que a participação ativa do cuidador em dinâmicas associativas, o comparecimento a atividades psicoeducacionais e o vínculo territorial a áreas metropolitanas com recursos comunitários diminuem o nível de sobrecarga do cuidador. **Conclusão:** Finalmente, destaca a importância e responsabilidade da enfermagem comunitária com o objetivo de prevenir os níveis de sobrecarga e aumentar os de saúde; além disso, é realizada uma série de propostas no sentido de favorecer as redes de apoio social, combinar tratamentos e aumentar os programas de saúde pública em contato com a comunidade.

DESCRITORES

Transtornos Mentais; Cuidadores; Família; Apoio Social; Enfermagem em Saúde Comunitária.

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ANEXO 7.7. Artículo 2. Risk factors associated with the family care of people with serious mental illness

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Risk factors associated with the family care of people with serious mental illness

Ángela Carbonell [1], José-Javier Navarro-Pérez [2], Maria-Vicenta Mestre [3]

[1] Department of Social Work and Social Services, University of Valencia (Spain)
[2] Inter-University Research of Local Development (IidL), Department of Social Work and Social Services, University of Valencia (Spain)
[3] Department of Basic Psychology, University of Valencia (Spain)

Correspondence:
Department of Social Work and Social Services
Tarongers Avenue 4B,
46022 Valencia
Office 1D19 - University of Valencia (Spain)
Angela.Carbonell@uv.es

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Abstract

Background: The aim of the present study is to analyse the variables associated with the family care of people diagnosed with serious mental illness.

Material and Methods: A cross-sectional study was carried out involving caregivers of people with serious mental illness (SMI) who were known to the mental health services in Valencia (España) and associations for those with SMI. The sample comprised 417 caregivers who completed a sociodemographic questionnaire and the Zarit Burden Interview. Bivariate analyses (t-test, analysis of variance and Pearson correlation) were performed, as was a multiple linear regression model. Values of $p < .05$ were considered significant. The study was carried out in accordance with the recommendations of the ethics committees of the participating institutions.

Results: The statistical analyses showed significant associations between the sociodemographic and clinical variables of the caregivers and patients and the burden felt by caregivers of people with SMI. The importance of both formal and informal social support stands out as a protective factor against the consequences of the illness's impact on the main caregiver.

Conclusions: The role of spaces of mutual support is crucial. The results suggest that family psychoeducational programmes should be created, applied and evaluated in all mental healthcare services so as to reinforce training in mental health matters and provide support and assessment to caregivers in order to ease their burden.

Key words: *Care, social support, mental health, associationism.*

Introduction

Mental healthcare has undergone far-reaching epistemological and practical changes, representing a long and complex historical and cultural process. Indeed, the World Health Organization has for many years been questioning the role of psychiatric institutions and healthcare processes dealing with mental health. Until the mid-twentieth century the only treatment provided by psychiatry was hospitalization for indefinite periods of time. The appearance of new community healthcare models for people with mental illness, based on criteria of quality of life and decent care, and the incipient development of psychopharmacology marked the beginning of a move towards psychiatric deinstitutionalization (1) involving the closure of psychiatric hospitals and the release of people with serious mental illness (SMI) into the community (2).

Despite the fact that the mental healthcare system in Spain has fought to provide the necessary support services, the family continues to be the main source of care for people with SMI. Although family care can have a positive impact on the rehabilitation and recovery of these people, the scientific literature is rich in studies that show that their caregivers can experience strong feelings of burden and objective and subjective distress (3) as a result of their many responsibilities and the exhaustion these induce. Apart from the mental and emotional impact, the care burden involves anxiety-provoking aspects such as economic cost, shame, stigma and feelings of guilt and self-pity.

Taking into account the negative repercussions of psychiatric family care, studies have analysed how the care burden can be influenced by the sociodemographic and clinical characteristics of the patients and caregivers and how these affect the caregivers' quality of life (4). The feminization of care makes it difficult to provide significant evidence of the burden according to gender (5). Nevertheless, it is the mother who usually performs the task as a moral obligation in a patriarchal society, which makes it difficult to reconcile work and care. A study carried out in Spain showed that the parents of sick people feel greater levels of burden and worry more about their future than other family members (6). Studies have associated the lengthy nature of chronic illnesses and the ageing of caregivers with an enormous family burden, revealing higher levels of burden in caregivers whose family members have been sick for a long time or whose illness began at an early age, and with less autonomy and more active symptoms that require a greater number of hospitalizations (7, 8). Other demographic characteristics of the caregivers, such as economic income and level of education, have been shown to correlate with their psychological and physical burden. Social support, however, is considered to be a protective factor (9) since it makes it possible to understand the compensation and adjustment mechanisms used to deal with the difficulties of care and to reduce the harmful effects that emerge as a result of providing continuous care for someone.

The aims of this study are (1) to identify the characteristics of the caregivers of people with SMI, (2) to identify the level of burden, and (3) to analyse the variables associated with family care in mental health.

Material and Methods

A descriptive cross-sectional study of family caregivers of people with SMI was carried out.

-Participants

The study population consists of family caregivers. The inclusion criteria were (1) resident in Valencia (España), (2) caregiver of a person diagnosed with an SMI according to the DSM-5 and responsible for the associated tasks, (3) age ≥ 18 years, (4) no psychiatric history, (5) family member or relative, (6) care ≥ 6 months, (7) absence of remuneration for the care provided, and (8) voluntary participation in the study. Those who did not complete the questionnaires correctly and those who declined to participate were excluded. 417 family caregivers of people with SMI were included as participants in the study.

-Instruments

The main instrument used was the Zarit Burden Interview (ZBI) (10) as adapted into Spanish by Martin *et al.* (11), which measures the extent of the caregiver's burden. Although this has mainly been used with the caregivers of people with dementia, the extensive literature (12,13) endorses its use also with caregivers of people with mental illness. It consists of 22 items recorded using a Likert scale from 0 (never) to 4 (nearly always). The results add up to a total score of between 0 and 88 points. Higher scores indicate greater caregiver distress. For the present study the scale obtained a Cronbach's alpha coefficient of .91.

Included were the sociodemographic characteristics of the caregivers (sex, age, marital status, relationship to the sick person, employment situation, presence of health problems, active associationism, psychoeducational interventions and geographical setting) and of the people cared for (age, sex, diagnosis, number of years since SMI was diagnosed, degree of disability and care received).

-Procedure

The participants were recruited via mental healthcare facilities and associations of patients and family members of people with SMI in Valencia (España). An appeal was made for volunteers and information about the study was provided. Once the participants had been selected, individualized interviews were arranged, in which the Spanish version of the ZBI questionnaire was administered and sociodemographic and clinical details collected. Participants received no monetary compensation for taking part in the study. Data were collected between June and December 2018.

The study was carried out in accordance with human rights protection protocols and satisfied the ethical requirements for research approved by the institutional review board before the participants were recruited. The family caregivers were sent a letter that explained the details of the study and informed them that they had the right to interrupt or leave the study at any time and for any reason, in accordance with the Declaration of Helsinki. All participants gave their informed consent in writing before data were collected.

-Data analysis

The IBM SPSS Statistics 25 package was used for the data analysis. The level of statistical significance was established as $p < .05$. Descriptive statistics (percentages, means and standard deviations) were used to describe the sociodemographic characteristics of the caregivers and the people being cared for. The relation between sociodemographic characteristics and burden was identified. Inferential analysis involving t-tests and ANOVAs was used to identify statistically significant differences between the ZBI and the nominal variables. Correlations between continuous variables were analysed using the Pearson correlation coefficient. Finally, those variables that showed a statistically significant association were included in a stepwise multiple linear regression analysis to determine the predictive factors for caregiver burden.

Results

-The participants' sociodemographic characteristics

The study sample comprised 417 family caregivers of people with SMI, 72.2% of whom were women. Ages ranged between 18 and 89 years, with an average of 60.82 (SD = 13.46). Generally speaking, the participants in the study were the parents of those looked after (78.7%) and were married (52.8%) or divorced (14.9%). Most were not in paid employment (59.7%) and 49.2% had previously been caregivers of another sick person. The participants' sociodemographic characteristics are listed in Table 1.

The general profile of the person receiving care was male (69.8%) with an average age of 38.78 years (SD = 12.88; range = 16-80 years). All those being looked after had been diagnosed with an SMI – according to DSM-5 criteria – by psychiatric staff belonging to the public healthcare services in Valencia (España). The most common diagnoses were schizophrenia (62.1%), personality disorder (14.9%) and bipolar disorder (12.2%), and patients had had the illness for an average of 17.22 years (SD = 13.08). In addition, 49.4% had a recognized disability that affected their personal autonomy to a high degree.

Table 1: Sociodemographic characteristics of the study participants.

Variable	**n = 417**
Age (years)	60.82±13.46
Sex (female)	72.2%
Marital status	
Married	52.8%
Divorced	14.9%
Single	12.1%
Widow(er)	21.5%
Paid employment (yes)	40.3%
Presence of health problems (yes)	41.2%
Relation to the person looked after	
Parent	78.7%
Sibling	12.9%
Daughter/son	4.1%
Intimate partner	3.4%
Aunt/uncle	1%
Active associationism (yes)	14.1%
Previously cared for another relative (yes)	50.8%
Psychoeducational training (yes)	54.4%

Source: Own.

-Caregiver burden and associated variables

The overall average score for burden was 45.79 (SD = 17.09, range 10-80), with 14% of caregivers registering no burden at all. The rest showed light (24.9%) and intense (61.1%) levels.

Comparison of means tests indicated there were variables with values of statistical significance $p > .05$, which included marital status, having a chronic illness, having previously cared for someone else, and family relationship. The analysis established differences depending on the participants' sex and care burden (t = 1.932; $p < .05$), with men obtaining an average score of 48.53 (SD = 18.06) and women 44.76 (SD = 16.64). Caregivers in paid employment felt significantly higher levels of burden (M = 49.96; SD = 17.44) than those who were not active (t = -4.133; $p < .05$). Lower levels of burden were associated with caregivers who had taken part in psychoeducational interventions (t = 12.978; $p < .05$) and/or were members of an association (t = 13.724; $p < .05$). Geographical setting was also significantly related with the caregiver's burden (t = -5.962; $p < .05$), with caregivers living in metropolitan and rural areas obtaining an average score of 50.04 (SD = 16.33) compared to the 40.32 (SD = 16.55) of those living in towns and villages.

As far as the variables for the person looked after are concerned, the t-tests indicated that there were differences in the level of burden depending on their sex (t =

-2.096; $p < .05$), with caregivers who looked after women showing higher levels (M = 48.37; SD = 16.14) than those who looked after men (M = 44.66; SD = 14.41). Similarly, the caregivers of people who received continuous care in public mental healthcare facilities had an average burden score of 33.29 (SD = 14.143), while those who looked after people who did not had an average of 51.97 (SD = 14.93) (t = -12.411; $p < .05$). The descriptive inferential analysis found that the mental illness diagnosis of the person looked after also had a significant effect on the caregiver burden, F (6, 413) = 3.974, $p < .05$, $\eta^2 = .056$), with very high levels being found in caregivers of people with personality disorder (M = 54.31; SD = 12.49) compared to other diagnoses such as schizophrenia (M = 43.27; SD = 17.14).

Pearson correlation analysis (Table 2) found negative associations between the care burden and age (r = -.147; $p < .05$), with levels of burden diminishing as the caregiver's age increases. No significant relations were found for the disability and age of the person cared for. However, the years of duration of the illness correlated positively with burden (r = .175; $p < .05$).

To determine which variables contributed with significant unique predictive variance, the significant predictors were included in a multiple linear regression. As can be seen in Table 3, six regression models were constructed, revealing that the factors significantly associated with the highest burden scores were (1) participation in psychoeducational interventions, (2) associationism, and (3) continuous healthcare. The regression was highly significant (adjusted R2 = 0.41; F = 3, 97.214; $p < .05$).

Discussion

The family is the main support system and takes on the responsibility of caring for the patient in the community. The present investigation provides new evidence of the magnitude of the care burden, identifies factors associated with it and analyses the sociodemographic profile of 417 family caregivers of patients with SMI treated in different healthcare services in Valencia (España)

As far as the study's first aim is concerned, the sociodemographic characteristics of the sample are similar to those in other studies on caregivers of patients with SMI (14,15), in which the predominant profile is that of a woman just entering old age, married, without paid employment and with no chronic pathologies. Considering this, it is clear that there is inequality in the provision of care since it is mainly carried out by women, and this makes these women a collective that is vulnerable to the consequences resulting from the work they do. 72.2% of care is in the hands of women. Although the results of this study indicate that it is more usual for them to take on the task of caring (M = 44.76), the men obtained a higher average score (M = 48.53) for burden. Meanwhile the profile of the person with SMI matches that in Kate *et al.* (16): male, adult, diagnosed with schizophrenia, living with parents, and with the mother as the mainstay of care and attention.

Table 2: Pearson correlations for the dimensions of the variables analysed.

	ZBI	Age	Age SMI	DD
Age	-.147**			
Age SMI	.059	.216**		
DD	.082	.209**	.465**	
Years of illness	.175**	.301**	.478**	.321**

ZBI = Zarit Burden Interview; Age SMI = Age of person cared for; DD = Degree of disability.
**. The correlation is significant at a level of 0.01 (bilateral).
Source: Own

Table 3: Linear regression of the burden of the family caregiver of people with SMI.

Model	Unstandardized coefficients		Standardized coefficients	t	Sig.
	B	Standard error	Beta		
(Constant)	54.739	.873		62.715	.000
Psychoeducational training	-14.614	2.134	-.299	-6.848	.000
Associationism	-11.659	1.852	-.340	-6.296	.000
Continuous healthcare	-4.838	1.991	-.133	-2.430	.016

* Dependent variable: ZBI.

The analysis of caregiver burden produced an average score of 45.79, and three-quarters of the population surveyed registered intense levels of burden on the ZBI, revealing that the caregivers of people with SMI felt a significant burden similar to that found in other studies in the literature (17,15), which warn that this population could be at risk of being overwhelmed.

In this study the caregiver burden is associated with sex and age, with the highest levels being found among male and younger caregivers, unlike in other recent investigations (18,19) that indicate that looking after women and older patients are sources of stress and factors predictive of burden. Following Blanco *et al.* (20), this could be because inexperience and the opportunity costs of care may cause a feeling of burden in younger male caregivers. Another factor associated with caregiver burden was the problem of reconciling working life with care (21). Both the existing literature (22) and the results of this investigation describe characteristics typical of SMI (diagnosis, prognosis, years of illness, etc.) as being factors that induce feelings of burden in the caregiver. Hence the findings relate disorders with more complex symptoms (such as personality disorder) and the years of duration of the illness with greater levels of distress in the caregiver.

Despite the fact that the literature has focused mainly on the pathogenic factors of care, the results of the regression analysis showed that the variables connected with formal and informal social support were the most important mediator variables for caregiver burden (4,23). Access to continuous specialist healthcare, associationism and psychoeducational interventions for family members determined the burden levels of the caregivers, working as protective factors against the stressful impact of providing care. As argued in earlier studies (16,23,24), caregivers who perceive that they obtain sufficient support from institutions, family members and friends have a better quality of life and feel less distress in connection with the work they do.

-Limitations

The present study is subject to two limitations. The cross-sectional nature of the investigation made it possible to establish a predictive model for burden. However, longitudinal studies are more suitable for verifying the predictive factors of caregiver burden. Another important limitation was the non-existence of specific resources aimed at the caregivers and family members of people with SMI. This also meant that the sample was obtained in two blocks: from family associations of people with SMI and the public mental healthcare services whose family members agreed to participate in the study.

Despite the above limitations, this study has revealed a significant relationship between the sex, age and employment situation of the caregivers, the age and diagnosis of the patient, the years of duration of the illness and the caregiver burden of those looking after people with SMI. Social support stood out as a protective factor for care in a wide, representative sample of caregivers, allowing interventions to contribute to lessening the burden felt by the caregivers of people with SMI.

Today the support the public system gives is not enough. Although the government does provide resources for people with SMI and their family members, these resources are still limited and poorly funded. Families stand in for the lack of public resources earmarked for people with SMI. Thus patients remain with their families and this makeshift arrangement becomes an end in itself, even though the actual root of the problem is not tackled. Instead, problems are dealt with as they appear. The family is not given even the minimum resources to provide suitable care in each case. The consequences of informal care for the people that provide it continue to be a common challenge, and the response needs to involve the creation of real integrated healthcare policies aimed at both people with SMI and their caregivers. The state should promote public policies providing real support for family members who perform these tasks for other family members. This support should include rehabilitation services, psychosocial care, education, and training in carrying out both care and self-care tasks, and be provided not only through the mental healthcare services but also via other psychosocial healthcare facilities.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

ANEXO 7.8. Artículo 3. The care crisis in Spain: an analysis of the family care situation in mental health from a professional psychosocial perspective

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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	– 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	– 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	– 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 others 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.

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ANEXO 7.9. Artículo 4. Challenges and barriers in mental healthcare systems and their impact on the family: A systematic integrative review

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REVIEW ARTICLE

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

Ángela Carbonell MSW, PhD Candidate[1] | **José-Javier Navarro-Pérez PhD, Associate Professor**[1] | **Maria-Vicenta Mestre PhD, Professor**[2]

[1]Inter-University Research of Local Development (IidL) and Social Work and Social Services Department, University of Valencia, Valencia, Spain

[2]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, Vatansever, 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 & Shahrbabaki, 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 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.

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.

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 & Knafl, 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 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.

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*

A narrative synthesis of the sources was then carried out using inductive content analysis (Finfgeld-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 (CCRBT) (Higgins et al., 2011) was also used to assess the MQ of studies that included quantitative results. The CCRBT 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.

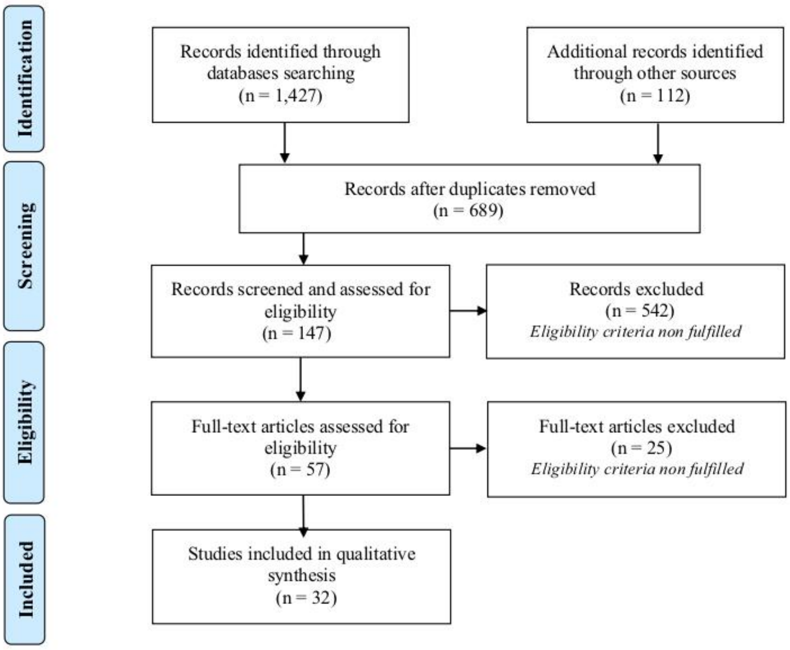

FIGURE 1 PRISMA 2009 flow chart (Moher, Liberati, Tetzlaff, & Altman, 2009) [Colour figure can be viewed at wileyonlinelibrary.com]

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[a]	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[b]	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[a]	Mixed-methods	103 caregivers and 6 consultant psychiatrists	BMC Health Services Research	JCR	1.932	Low risk of bias
Ambikile and Iseselo (2017)	Tanzania[a]	Qualitative	7 service providers, 7 people with SMI and 16 caregivers	BMC Psychiatry	JCR	2.666	High
Arandjelovic et al. (2016)	Australia[b]	Review		Australian & New Zealand Journal of Psychiatry	JCR	5.000	High
Athié et al. (2016)	Brazil[b]	Mixed-methods	18 health managers and 24 professionals	BMC Health Services Research	JCR	1.932	Low risk of bias
Azman et al. (2019)	Malaysia[b]	Qualitative	15 family caregivers of people with SMI	International Social Work	JCR	0.603	High
Balhara et al. (2016)	France, Spain, Israel[b] and India[a]	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[a]	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[b]	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[b]	Quantitative	95 caregivers of people with SMI	Journal of Gerontological Social Work	JCR	0.849	Low risk of bias
Hanlon et al. (2017)	Ethiopia[a]	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[a]	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[a]	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[b]	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[b]	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[a]	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[b]	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[a]	Review		International Journal of Culture and Mental Health	SJR	0.327	Moderate
Saymah et al. (2015)	Gaza[a]	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[b]	Review		Physis	SJR	0.243	Moderate
Tsui and Tsang (2017)	China[b]	Qualitative	Eight people with SMI and eight caregivers	Psychiatry Research	JCR	2.208	High
Valentini et al. (2016)	Germany[b]	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[b]	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[b]	Qualitative	13 users of mental health services aged over 18	Community Mental Health Journal	JCR	1.159	High
Wong et al. (2016)	Japan[b]	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.

[a] Low- and middle-income countries.

[b] 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, bureaucratised 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; Calvó-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 Calvó-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 socioeconomic 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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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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