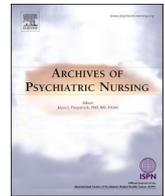


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# Perceived mental health and emotional trajectories of long-term family caregivers of persons with mental conditions: A mixed-methods study

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## ABSTRACT

**Aims and objectives:** To explore the emotional experience and the perceived mental health of experienced family caregivers of people with mental disorders.

**Background:** Family caregiving for individuals with mental disorders differs from other health conditions, as it implies a burden, deterioration in physical and mental health, stigma and a perceived lack of support from mental health services.

**Methods:** A mixed-method study was undertaken with family caregivers of people diagnosed with mental disorders.

**Results:** A total of 13 experienced family caregivers were included in the study. The qualitative data were classified into two major themes: emotions and perceived mental health. Emotions included five categories: irritability, painful emotions, pressure, emotions orientated towards coping, and positive emotions. The perceived mental health status embraced five categories: anxiety, burden and exhaustion, needing psychological or psychiatric treatment, insomnia and suicidal thoughts. An emotional path could be constructed from their discourses, starting with lack of control or irritation that evolved towards resignation, peace or satisfaction. The quantitative analysis partially replicated the qualitatively reported anxiety, depressive symptoms and insomnia.

**Conclusion:** Past and present emotions related to caregiving described by experienced family caregivers were identified. Their emotional trajectories converged in that negative emotions gave way to emotions towards coping, which in turn were followed by positive emotions. The participants' descriptions about their mental status were partially reflected through objective mental health measurements.

**Relevance to clinical practice:** More support from mental health services could help caregivers to progress in their emotional trajectory towards coping, and improve their caregiving knowledge and skills. Mental health nurses have a role in patients and caregivers education and in the promotion of caregivers' psychological wellbeing.

## What is known on the subject:

- Family caregiving for people with diagnosed mental disorders differs from other health conditions. It implies not only the burden and deterioration of health but also stigma and a perceived lack of information and support from the mental health services.

## What the paper adds to existing knowledge:

- The family caregivers of people diagnosed with mental disorders described positive and negative emotions, and an emotional path could be constructed from their discourses, starting with a lack of

control or irritation that evolved towards resignation, peace or satisfaction.

- The caregiving process can impact mental health, mainly causing symptoms of anxiety and insomnia.

## What are the implications for practice:

- The family caregivers' needs must be assessed and met by mental health professionals to improve their health and care experience and subsequently the care they provide.

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## Background

Family caregiving for individuals with mental disorders is a source of burden that has been studied since the psychiatric reform that led to deinstitutionalisation in the early 1980s, when psychiatric care was shifted towards the community, and still receives researchers' attention (Di Lorenzo et al., 2021; Koç et al., 2021; Ribé et al., 2018; Tamizi et al., 2020). This burden differs from other health conditions, as for families it implies not only a deterioration in physical and mental health (Thunyanadee et al., 2015) but also stigma (Allerby et al., 2015; Yin et al., 2020) and a perceived lack of information and support from the mental health services (Graneheim and Åström, 2016; Olasoji et al., 2017; Ribé et al., 2018; Cheng et al., 2020; Liu and Zhang, 2020). Caregivers rarely receive adequate preparation for their role (Schulz & Eden, 2016).

The emotional experience of family caregiving for a person with a mental disorder has been studied in various precise situations faced by caregivers, such as having a relative diagnosed with early psychosis, non-compliance with treatment, stigma, psychiatric hospitalization, caring as young caregivers, and shared decision-making. Caregiving for people with mental disorders carries a positive and negative emotional impact, as described by Shirraishi and Reilly (2019) in their systematic review. Various studies have described negative emotions such as a sense of duty (Weimand et al., 2013), sacrifice (Graneheim and Åström, 2016), sorrow (Ali et al., 2012; Olwit et al., 2015), obligation, pressure and exhaustion when involved in the shared decision-making regarding their relative (Huang et al., 2021), distress as a reaction to hospitalization of their relative (Weller et al., 2015) and even fear, distrust or insecurity when the person was not compliant with their psychiatric medication regime (Du Plessis et al., 2021). Other studies have reported positive feelings ranging from admiration, personal growth, love and compassion (Weimand et al., 2013) satisfaction, a sense of strength, value and accomplishment (Liu and Zhang, 2020). On the other hand, a lack of emotional coping among family caregivers was concluded by a meta-synthesis by Ntsayagae et al. (2019) including 10 studies undertaken in several African countries.

Caregiving can also impact on the social sphere. It can cause changes in the family dynamics due to disconnection with other family members (Caqueo-Urizar, Alessandrini, et al., 2017), imply the loss of a personal life due to caring for their relative (Liu and Zhang, 2020), generate self-reproach when prioritising one's own interests (Weimand et al., 2013) and the feeling of being cut off from society after losing friends or social contacts (Ntsayagae et al., 2019). Other studies reflected the support for caring from within the family and in support groups (Cheng et al., 2020; Bishop & Greeff, 2015). The family's economic status might worsen as they have to meet the needs of the diagnosed persons that they do not cover themselves (Caqueo-Urizar, Alessandrini, et al., 2017; Huang et al., 2021).

Caregiving to individuals with mental disorders also impacts on the caregivers' mental health. A cross-sectional study undertaken with 454 caregivers of persons diagnosed with schizophrenia in Hong Kong concluded that 78 % had experienced anxiety and 45 % had insomnia (Wan & Wong, 2019), while another study carried out in Israel with 78 caregivers of people with chronic psychotic disorders identified depression in 26 % of the caregivers (Rachamim et al., 2022). A recent systematic review by Lima-Rodríguez et al. (2022) concluded that anxiety, insomnia and depressive symptoms were associated with caregivers' quality of life. In this line, according to a cross-sectional study including 395 caregivers by Zhou et al. (2021), the caregivers' psychological wellbeing facilitated active coping and seemed to be related to their caregiving knowledge and skills.

To the best of our knowledge, no previous studies have approached the emotional experience and the perceived mental health of experienced or long-term family caregivers of people with mental disorders, so this became our general objective. Our research questions were: (i) what are the past and present emotions of experienced family caregivers related to caregiving? and (ii): do their perceptions of their own mental

health correlate with objective mental health measurements? The specific objectives included:

- To identify the positive and negative emotions of family caregivers.
- To identify the mental health status of family caregivers.
- To explore the emotional trajectory of caregivers along with the caring experience.

## Methods

### Design

A mixed-method approach was conducted. In a mixed-methods study, both qualitative and quantitative data are combined, which helps to provide a more complete picture than a standalone quantitative or qualitative study, integrating the benefits of both approaches (Shorten & Smith, 2017). It requires a purposeful mixing of methods in the data collection, analysis and interpretation of the evidence, and is appropriate for answering research questions that neither quantitative nor qualitative methods could answer alone (Halcomb & Hickman, 2015). Considering that in this research we were attempting to correlate the participants' perceptions regarding mental health with objective measurements, triangulation was considered the best design for this study. This involves combining several research methods to study one thing from different perspectives. They overlap each other somewhat, are complimentary at times and contrary at others. This approach provides a better understanding of the phenomenon under study and is particularly useful in behavioral, health and social sciences (Creswell & Plano Clark, 2017).

The participants of the study were family caregivers of people with mental disorders living in Valencia, Spain. The study was carried out in the Organisation for the integral health of people with mental disorders (the Spanish acronym is ASIEM), a non-governmental organisation founded in 1999 with >600 members, most of whom are people with a psychiatric diagnosis and their relatives. Its activities are aimed at the people affected by a mental disorder and their families.

The inclusion criteria were: being a family member and primary caregiver of a person with a mental disorder (if this responsibility was equally shared with another person, the two of them could take part in the study); being able to understand and express themselves in Spanish; being members of the organisation ASIEM or attending the organisation meetings and being willing to participate. Those with a cognitive impairment that prevented them from answering the interview questions were excluded.

The participants were recruited through convenience sampling. One of the authors (V.S.-M., female, RN, MHN, PhD, lecturer at the University of Valencia) contacted the aforementioned organisation and requested permission to introduce the study and recruit volunteers. She was invited to attend the first minutes of three ordinary meetings with different family caregivers who were members of the organisation (held in November and December 2019). Before the meetings started, she addressed the attendees to briefly introduce the research group, explain the purpose of the study and invite those interested in participating. She left a notebook in the room and went out, so the volunteers could provide their name and contact number for the research team to telephone them in order to arrange an interview. At the end of the meeting, the notebook was collected by a responsible person, who then returned it to the first author. This meant that the potential volunteers did not feel under pressure to take part in the study. The reasons for not participating were not explored at this point. Not all of those who volunteered to participate were interviewed, as data saturation was achieved. The research team thanked the volunteers who did not participate through a telephone call.

A total of 13 family caregivers were included in the study. The sample size was determined when data saturation was reached, *i.e.* when the information obtained was repeated and did not provide new aspects

(Saunders et al., 2018). In this study, data saturation was achieved with 12 interviews, and one more participant was interviewed to confirm this.

### Data collection

#### Qualitative methods

Semi-structured interviews were used for data collection in the qualitative branch of the study. The purpose was to describe the perceived mental health state and the emotional impact of family caregiving of people with mental disorders.

The thirteen interviews were carried out on weekdays between December 2019 and February 2020. Each interview was scheduled at a convenient time and place for the volunteers. Only the interviewee, the interviewer (V.S.-M.) and an observer (a Degree in Nursing student) were present at the meetings to enable the participants to feel free to express themselves. The observer took notes on the participants' nonverbal expressions in order to maximise the information obtained. None of the participants had any prior relationship with any of the researchers. The participants were invited to suggest a place for the meeting or come to a meetings room at the Faculty of Nursing and Chiropody, with easy access and optimal acoustics. They were invited to choose the meeting location to allow them to feel comfortable and to facilitate cooperation. Three interviews took place at the participants' homes, one in the organisation office and nine at the Faculty.

The study was explained in detail to each participant before each interview began. They were then offered the opportunity to sign the informed consent and permission to register the conversation was obtained. All the volunteers agreed to sign the informed consent and to have the conversation audio recorded. The semi-structured interviews followed a script to ensure that the research objectives were met. The first question aimed to determine knowing each participant's context and caregiving situation, while the others focused on the specific objectives of the study. The researchers took field notes during the interview.

#### Data analysis

First, qualitative analysis was performed. The textual corpus was prepared for reading, and the recordings and the notes from the interviews literally transcribed. The interviews were transcribed by the same person who observed them. For the content analysis, the researchers (S.C., V.S.-M. and O.C.) pre-analysed the texts. The pre-analyses were performed through several readings of the primary documents, and the first list of topics was created. The quotations were then generated, highlighting the most relevant text segments, and coded. Relationships were then established, and code categories and themes were created to interpret the phenomenon being studied based on the informants' discourses. Finally, we verified that the transformed data matched the original ones.

The coding was carried out inductively and deductively. *A priori* topics were defined when the conceptual framework was made, and other topics or codes emerged as the analysis was carried out (Pope et al., 2000). The content analysis included triangulation of the researchers to increase the rigour of the analyses and to avoid the potential bias caused by the expectations of the first author, and as such V.S.-M. and S.C. or O.C. analysed each interview. For the correct interpretation of data, the third researcher reviewed the transcription and participated in the decision when consensus was not achieved. Atlas.Ti (version 8) was used for the analysis of the qualitative data. This software is a tool for content and discourse analysis of qualitative data that facilitates management, organisation, and interpretation (Soratto et al., 2020). The Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed (Supplementary file 1) (Tong et al., 2007).

#### Researchers' reflexivity

The researchers had training in qualitative research undertaken on master's degree or PhD courses, and all had previous experience performing qualitative studies through focus groups and interviews.

#### Quantitative methods

##### Data collection

The quantitative data collection started after each qualitative interview. First, a form including the family caregivers' sociodemographic and clinical data was completed, and several quantitative instruments were administered to the participants. These questionnaires measured the following variables: anxiety or depressive symptoms (Goldberg's Anxiety and Depression Scale) and sleep quality (Athens Insomnia Scale). Considering that the questionnaires might invite the participants to express some aspects not reflected in the interview, this part of the data collection was also registered.

The Anxiety and Depression Scale was presented by Goldberg et al. (1988) as a screening instrument for adults and older adults, comprising up to 18 items. There are four screening questions for anxiety and four for depression. If there are two or more affirmative answers to the initial questions on the anxiety scale (one or more for the depression scale), five more questions need to be asked. The final score is the number of affirmative answers for each subscale. Individuals with anxiety scores of five or depression scores of two are considered to have a 50 % chance of clinically significant disturbance, and the probability rising sharply above those scores. This instrument was validated in Spanish by Montón et al. (1993), showing adequate sensitivity (83 %) and specificity (81.1 %), and with a 95 % positive predictive value.

The Athens Insomnia Scale is a self-report questionnaire used as a screening mechanism for sleep disturbances. The full scale is based on the International Classification of Diseases (ICD-10), with eight items and a score ranging from 0 to 24 (the cut-off point is six, and higher scores suggest a more severe problem). It was validated by Soldatos et al. in 2000 and validated in Spanish by Gómez-Benito et al. in 2011 with acceptable psychometric properties (Cronbach's alpha was 0.86).

The Zarit Caregiver Burden Scale (Zarit et al., 1980) is a self-administered 22-item questionnaire with each item scored from 1 ("none") to 5 ("nearly always"). The score may range from 22 to 110, representing 3 levels of burden: no burden (22–46), mild burden (47–55) and severe burden (56–110). This instrument was validated into Spanish in 1996 (Martín-Carrasco et al., 1996).

The data from each psychometric scale (Goldberg's Scale, Athens Insomnia Scale and Zarit Caregiver Burden Scale) were quantified according to the published instructions of those scales, and the score was obtained for each caregiver. It means that for each caregiver we calculated the score of each scale reflecting the severity of anxiety, depressive, insomnia symptoms and caregiver burden. A higher score means a more severe symptomatology on all scales.

#### Ethical considerations

The research was approved by the Human Research Ethics Committee of the University of Valencia on September the 5th, 2019 (protocol number 1046761). Confidentiality of data was warranted. Permission for recording the interviews was gathered, and all the participants signed informed consent once they received all the needed information about the details of the study.

#### Results

A total of 13 caregivers participated in the study, whose socio-demographic characteristics are described in Table 1.

The information obtained through the interviews was classified into two major themes: emotions and the perceived mental health of family caregivers. In the second theme, perceived mental health status, five categories were identified: anxiety, burden and exhaustion, needing

**Table 1**  
Sociodemographic characteristics of the participants.

Code	Age	Gender	Marital status	Years caring	Person cared for	Living with the person cared for	Diagnosis of the person cared for	Employment status
C1	61	Male	Divorced	15	Daughter	No	Bipolar disorder	Retired
C2	63	Female	Married	20	Brother	No	Psychotic disorder	Retired
C3	71	Female	Married	20	Son	Yes	Severe personality disorder	Retired
C4	70	Female	Married	6	Son	Yes	Psychotic disorder	Retired
C5	75	Female	Widow	25	Son	Yes	Psychotic disorder	Retired
C6	79	Female	Married	24	Son	Yes	Psychotic disorder	Retired
C7	50	Female	Married	7	Son	Yes	Obsessive-compulsive disorder	Working
C8	60	Female	Married	10	Sister	No	Bipolar disorder	Working
C9	74	Male	Widower	10	Daughter	Yes	Psychotic disorder	Retired
C10	72	Female	Married	10	Son	Yes	Psychotic disorder	Retired
C11	66	Female	Married	14	Daughter	No	Psychotic disorder	Retired
C12	60	Female	Married	3	Son	Yes	Psychotic disorder	Working
C13	60	Male	Married	3	Son	Yes	Psychotic disorder	Working

psychological or psychiatric treatment, insomnia and suicidal thoughts.

**Emotions**

The first central theme, emotions, was divided into five categories in which 15 codes were identified: irritability (two codes), painful emotions (four codes), pressure (three codes), emotions orientated towards coping (two codes) and positive emotions (four codes). The theme structure is described in Table 2. In the table, the emotions referred, either in the past, in the present, or both, have been indicated.

Two categories outlined the others in terms of frequency: pressure and emotions towards coping. More precisely, the most reported feelings among caregivers were pressure-nervousness, described in all the participants at a specific moment, resignation-acceptance, with 12 out of the 13 participants reporting feeling them, and fear with ten caregivers. Those were followed by uncertainty with eight participants.

**Irritability**

Two codes were identified in this category: lack of control and tension. The participants referred them almost exclusively in the past, before their relative was adequately diagnosed or treated, did not take the prescribed drugs, or presented exacerbations of the disorder.

Several participants indicated that, in the past, they felt a lack of control of the situation with their emotions running high. This happened when they were not able to control their nerves and reacted without thinking:

*C6: If someone is standing under lots of pressure, a moment arrives when they can explode like a balloon when it's pricked. That happens to me.*

Some participants also manifested a feeling of irritation and tension:

*C13: I did not realise our son was ill, and I thought he was being lazy. Our relationship went to the extremes of calling each other names and swearing at each other.*

**Painful emotions**

Four codes were classified as painful emotions: sorrow, hopelessness, feeling of guilt and loneliness.

The most common emotion within caregivers in this category was sorrow, which was felt not only in the past but also in the present:

*C12: I'm sorry for everything that has happened... I think I'm getting over the grief. It was tough for me when we were told the diagnosis because I read, was well informed, and could recognise the symptoms.*

The suffering was often accompanied by a feeling of guilt and remorse due to maintaining their everyday life, or for not realising the situation their relative was in earlier and therefore failing to react properly or accept the situation:

*C13: His mother and I have sometimes blamed ourselves; there's something we must have done wrong.*

*C5: When I arrived home from work, I felt guilty for having been working [...] My other son says I have guilt inside me.*

Some participants also reported a feeling of hopelessness with the situation:

*C1: I looked at the horizon and saw no end in sight.*

One participant said that she felt lonely during the care process due to a lack of understanding of the situation by the rest of the family:

*C11: My husband doesn't help with this. When he sees I am sad or nervous, the only thing he does is shout at me and blame me; he doesn't help*

**Table 2**  
Categories and codes identified through qualitative analysis for each participant in the past and present.

Categories	Codes	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	C12	C13
Irritability	Lack of control	X					P	X	X			X		
	Irritation	X									X	X	X	X
Painful emotions	Sorrow	X			P	XP		X	P	P	XP		XP	
	Hopelessness	X			P							X		
	Guilt	X	P	P	P	XP	P							X
	Loneliness in care				P	X			X	XP	P	P		
	Fear	X	XP	P	P	X	X	X			XP	XP	X	
Towards coping	Uncertainty					XP		X	XP	XP	X	P	X	XP
	Pressure -Nervousness	X	P	P	P	X	P	XP	XP	X	P	XP	XP	X
	Resignation – acceptance	P	P	P	P	P	P	P	P	P	P	P	P	
Positive emotions	Skepticism					P			P			X	X	
	Hope					P	P	P		P			P	P
	Calm	P				P			P					
	Control – strength	P				P				P				P
	Satisfaction		P								P			P

X: Emotions described as experienced in the past; P: Emotions expressed as experienced at present.

at all. [...] We have different views on care; he understands it differently, and doesn't help or support me.

C2: I have more brothers who live away and the truth is, they don't worry much about our family. I am the one who carries the burden.

#### Pressure

This category included three codes named nervousness, fear and uncertainty-concern.

Nervousness was accompanied by a feeling of being unable to cope with the situation, and sometimes they mentioned a feeling of stress, tension or anxiety:

C11: For me, it's daily anxiety, worry, and inner suffering knowing my daughter is not well and lives independently. It's a constant struggle. I've accepted it. I live with it. But no matter how much my therapist insists I have to live my life, I can't because she is my life.

Most participants felt fear for several reasons. For instance, some reported that they were afraid to leave their relative alone at home, even momentarily. Others felt afraid of their family member's reactions, especially when the situation was uncontrolled due to a lack of adherence to the drug treatment:

C2: I've been terrified because I don't know how far this could go.

C12: All this time, I've experienced so much stress. I suffered so much for my son; I thought he would let himself die.

Several caregivers felt an important degree of uncertainty and concern about the future. They felt worried about what the situation of their loved ones would be after they died or if they were unable to care for them.

C9: I worry that my daughter will have nothing to live on when I go.

#### Emotions orientated towards coping

Two emotions were considered in this category as they were perceived as essential steps towards acceptance or coping: incredulity and resignation.

Seven caregivers indicated a feeling of skepticism since in the past, they had faced extremely difficult situations, and now they lacked confidence about the future, and preferred to wait and see how the person with the illness progressed.

C5: I'm very optimistic but very realistic. Realistic as I am, I know miracles don't exist. So yes, I do see things clearly, but I'm always suspicious. Is this going to be the same afterwards? I don't know. The thought doesn't torment me, but I'm wary of saying it: let's see what happens.

Resignation was one of the emotions felt by most participants. Caregivers considered that they had to accept the circumstances they were facing, and their role was to care for their loved ones.

C7: I don't mind looking after my son because I think it's my obligation as a mother to be with him and to look after him, just like my daughter. I see it as something I have to do, and I do it, but I would like him to be a healthy and happy young man. But that's my lot, and I have to take it all in my stride.

#### Positive emotions or experiences

This category included four codes, namely hope, peace, control-strength and satisfaction.

Several caregivers had a feeling of hope. They were optimistic as they thought that the situation would improve in the future.

C7: I expect him to work and have his own life, even if he needs some [medical] control.

C6: I'm optimistic. I mean, I think this is a horrible time, but it can be remedied. If we can remedy it, we have to try to remedy it.

Another feeling reported by caregivers was calm.

C8: I have succeeded in being quiet, calm and having peace of mind.

Another positive emotion that emerged from the interviews was satisfaction. The caregivers indicated that they felt satisfied when helping others, and especially their family:

C2: I feel satisfied when I help my family, my people, the ones around me... Those are values that my family instilled in me.

C8: It's enough to be well enough to help her, and I think how lucky I am not to be ill.

Moreover, some family caregivers expressed control of their emotions, like a sense of domain. Sometimes it meant the ability to look happy in front of the rest of the family:

C5: I think that controlling my feelings and my character helped me. I always had to work, and working made me strong and aware. [...] I've always managed to get myself going, and it's been a driving force. I also try to be cheerful in front of others, with my children, grandchildren, and friends. I try to be happy in front of them.

In addition, they felt that their experiences gave them strength to cope with the situation:

C1: Our quality of life is lovely now. If another problem comes up, we are more prepared and we have another perspective for dealing with it.

#### Mental health

For the theme of "mental health status", five categories were identified: anxiety, burden, sleep disorders, the need for psychological/psychiatric treatment and suicidal thoughts. Triangulation was performed for these categories using three different instruments: the Goldberg Anxiety and Depression Scale, the Zarit Caregiver's Burden Scale and the Athens Insomnia Scale. The information from the qualitative and quantitative analyses is summarised in Table 3, including the caregivers' mental health self-perception identified through the qualitative and quantitative analysis for each participant.

Anxiety and sleep disorders were the self-reported mental health disorders most frequently described by the participants, and these disorders were present when the interviews took place. Anxiety was mentioned by nine participants, mainly in the present (eight), and sleep disorders were described by seven participants (six of them in the present). Three people said they were receiving psychiatric or psychological therapy at the time of the interviews. Two people described having a perceived caregiver's burden, and one person described suicidal thoughts. Some quotations reflecting these categories are listed below:

Anxiety:

CM3: From time to time, it happens, and I start feeling anxiety. I feel short of breath. So I try to breathe and calm down.

CM10: Now, I'm having palpitations. When I get upset, I feel them more in my chest.

Sleep disorders:

CM11: In the middle of the night, you open your eyes and think: oh, my god! How is she now?

CM13: All this has affected me, but I only need prescribed drugs to sleep.

Burden / exhaustion:

CM3: I always feel overworked.

CM4: The other day, my daughter came home, and I told her: I wish I could go away and leave your father in charge of the problem.

Psychological treatment:

CM12: I'd previously been treated by a therapist who helped me overcome other problems.

**Table 3**

Caregivers' mental health self-perception detected through the qualitative and quantitative analysis of each participant.

	Categories	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	C12	C13
Qualitative findings	Anxiety			P		X		X	XP	XP	XP	XP	XP	
	Burden – exhaustion	X										X		
	Needing therapy or psychiatric treatment	X		P	X					P		P	P	
	Insomnia				P		P	X			P	P	P	P
	Suicidal thoughts											X		
Quantitative findings	Treatment with psychotropic drugs	No	No	No	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes
	Goldberg Anxiety Scale score	0	0	3	6	0	8	0	0	0	3	9	0	8
	Goldberg Depression Scale score	0	0	6	5	0	0	0	0	0	0	8	0	4
	Total Goldberg Scale score	0	0	9	11	0	8	0	0	0	3	17	0	12
	Athens insomnia scale score	1	1	6	5	2	5	1	2	1	0	12	5	2
	Zarit caregiver Burden score	18	13	34	33	22	39	25	24	10	16	59	8	23

X: Perceived mental health problems experienced in the past. X: Perceived mental health problems experienced at present.

### Suicidal thoughts:

*CM11: I've been driving my car and thinking about flooring the accelerator. If my daughter hates me so much and there is nothing I can do, what am I doing here on Earth? I've thought of that several times.*

### Quantitative findings

Seven caregivers mentioned they were receiving treatment with psychotropic drugs or psychological therapy for anxiety, depression or insomnia at the time of the interview. The responses to the questionnaires administered to the caregivers suggested the presence of anxiety and depression in four participants, appearing together in three of them. Two participants screened positive for insomnia and one person scored a severe care burden, while the other 12 obtained scores compatible with no burden. Further details are provided in [Table 3](#).

The quantitative analysis of anxiety, using the Goldberg anxiety subscale screening partially replicated the qualitatively reported anxiety. On the one hand, caregivers C1, C2, C7, with no qualitative report of anxiety at the time of the interview scored 0 on the Goldberg scale. Caregivers C3, C10, C11 qualitatively reported current anxiety (score  $\geq 5$ ), but only C11 scored positive on the Goldberg anxiety scale. On the other hand, caregivers C4, C6 and C13 did not self-report any anxiety symptoms but scored positive on the scale, and caregivers C8, C9, and C12 qualitatively expressed experiencing anxiety, but scored 0 on the Goldberg subscale.

The depressive symptoms screened by the Goldberg depression subscale reflected that four caregivers could have clinically relevant depressive symptoms (score  $\geq 2$ ).

There was an overlap between qualitatively reported insomnia and the Athens insomnia scale (clinically relevant when the score  $\geq 5$ ) except for caregiver C3 (who did not self-report insomnia, but scored 6 on the Athens insomnia scale) and C10 (presented self-reported insomnia but scored 0 on the Athens Insomnia scale).

### Emotional trajectory

The emotions of the category irritability were described as having been experienced almost exclusively in the past. In contrast, painful emotions and pressure appeared in the past and the present. On the other hand, the codes reflecting “emotions orientated towards coping” and “positive emotions” were mainly identified in the present.

An emotional path could be described for the participants. The irritability and the painful emotions, mainly pressure, nervousness and fear, open the way for coping and positive emotions, which are most commonly resignation-acceptance and hope. Resignation – acceptance was described by 12 participants, although some of them were also experiencing lack of control (C6), sorrow (C4, C5, C8, C9, C10 and C12), hopelessness (C4), guilt (C2, C3, C4, C5 and C6), loneliness in care (C4, C8 and C9), fear (C2, C3, C4, C10 and C11), uncertainty (C5, C8, C9, C11

and C13) and nervousness (C2, C4, C6, C8, C10, C11 and C12).

Several participants (C1, C5, C3, C8) said that they could identify turning points in their lives that could have helped them make the transition from painful emotions to coping and positive emotions.

*C8: What happened was that my sister always wanted to be cared for by me. She never accepted anyone else. One year ago, she started allowing our cousins to help me care for her, and she understands we are a team and we all support each other. We are very close. I'm so grateful to them for all their help, because I used to think that I was alone, but I'm not, luckily.*

*C1: Eight months ago, after 15 years, my daughter was assigned a new psychiatrist, who changed her diagnosis and treatment. The change since then has been positive, we feel they have got the drugs right, and my daughter is infinitely better in all respects.*

When expressing their personal experience of care, some of the caregivers reported that their relatives were acutely unwell when the interview took place (C4, C10, C11).

### Discussion

To our knowledge, this is one of the first studies to focus on both the perceived mental health and the emotional experience of family caregivers of people with mental disorders using a mixed-methods approach.

The emotions most frequently reported by the participants in this study included pressure-nervousness, fear and uncertainty. Some of these emotions were reported in previous studies of family caregivers of people with mental health disorders (Olwit et al., 2015; Brain et al., 2018; Shiraishi & Reilly, 2019; Du Plessis et al., 2021). As in other studies (Ali et al., 2012), sorrow was a common painful emotion described by the participants, but it was not chronically reported by the participants in our study in contrast to Olwit et al. (2015), who recruited participants from a national mental referral hospital in Uganda. Several caregivers in our study also expressed concern about the future of the loved ones they cared for when they were no longer able to care for them, in line with Graneheim and Åström (2016), Liu and Zhang (2020) and Huang et al. (2021).

The participants in our study expressed emotions towards coping, such as resignation-acceptance, which were also reported by Olwit et al. (2015) and Peng et al. (2022) in a recently published study carried out in rural China. In addition, and congruent with previous research on caregivers of people with chronic mental disorders and other chronic conditions such as dementia and cancer, positive emotions, namely calm, hope, peace, control-strength and satisfaction were also identified in this study by ten caregivers (Balducci et al., 2008; Weimand et al., 2013; Olwit et al., 2015; Leow & Chan, 2017; Shiraishi & Reilly, 2019; Liu and Zhang, 2020; Peng et al., 2022). In our study, most family caregivers reported that they had experienced a turning point when they sought support from health professionals or family or when their relative

had started a new treatment that improved the control of their symptoms, or when their relative showed adherence to it. Nevertheless, it would be interesting to explore the specific mechanisms contributing to the onset of positive emotions in family caregivers.

In the social sphere, some participants described a feeling of guilt and remorse about maintaining their everyday activities, as also described by Weimand et al. (2013). Others suffered from loneliness due to a failure by other family members to understand the situation. This disconnection had been previously reported by Caqueo-Urizar, Alesandrini, et al. (2017).

Qualitative and quantitative analyses suggest that most family caregivers displayed a certain degree of mental discomfort after living for years with these chronic conditions and caregiving. This finding is consistent with previous research undertaken in family caregivers of people with schizophrenia nearly four decades ago (Thompson & Doll, 1982; Oldridge & Hughes, 1992). Accordingly, family caregivers of people with mental disorders are themselves at high risk of mental disorders and poor quality of life, suggesting they should also be recipients of holistic strategies of care (Chiao et al., 2015; Eters et al., 2008; Martín et al., 2015; Yu et al., 2020), as improving their quality of life might improve symptomatology and quality of life of their recipients of care (Caqueo-Urizar, Rus-Calafell, et al., 2017).

As regards the clinical significance of our study, half of the family caregivers enrolled in this study were receiving prescribed psychotropic drugs for insomnia, anxiety or depression. As in a previous study, insomnia was the most common self-reported psychiatric disorder (McCurry et al., 2015), and present in half of the interviewed individuals, as also found by Wan and Wong (2019). However, those authors found that depression was more prevalent among caregivers, affecting 78 % of them. It has been suggested that caregivers living with the care recipient are more likely to experience stress or anxiety than depression (Mahoney et al., 2005), which is consistent with the qualitative findings of our study. Some caregivers presented a dichotomy between what they expressed in the interviews and their results in the screening of psychiatric symptoms. Some of them were receiving treatment with psychotropic drugs, which might affect the scores of the screening. One participant reported having experienced suicidal ideation in the past. This finding is in line with a review in which the risk of suicide ranged from 2.7 % to 71 % of family caregivers of people with long-term illnesses and disabilities (O'Dwyer et al., 2021).

Non-pharmacological interventions have been regarded as potential methods for relieving caregivers' burden in some neurological diseases such as cerebral stroke (Legg et al., 2011). In other populations, non-pharmacological interventions have proven to be effective for family caregivers, including psychoeducation (Sin & Norman, 2013), mutual support programs (Chien & Norman, 2009), counseling (Shuler, 2014), and web-based or telephone interventions (Corry et al., 2019; Wilz et al., 2018). Caregiving knowledge and skills might influence the caregivers' psychological wellbeing (Zhou et al., 2021), meaning that controlled clinical trials in caregivers of individuals with mental disorders could be helpful for identifying means to reduce their mental health burden and thus indirectly improve the care they provide. Implementing these strategies is expensive and time-consuming, but they tend to be more effective than pharmacological treatment alone in managing psychological distress, burden and psychiatric symptoms in family caregivers. Considering the caregivers' characteristics (including socio-economic status and family support) and the relative's mental disorder and functionality could be helpful when designing non-pharmacological interventions. As regards the care burden, a recent meta-analysis performed in caregivers of people with schizophrenia reported a significant reduction in the care burden after non-pharmacological interventions. However, no differences were found in other aspects of caregiving, such as family support, family functioning or satisfaction (Chen et al., 2016), suggesting the need for a more goal-directed beneficial effect on the caregiving process.

When expressing their personal experience of care, some caregivers

said that their relatives were acutely unwell at the moment of the interview. This could explain the painful emotions such as fear or pressure reported during the interview by these participants. As in previous research, a heavier burden of care and worse mental status were observed among those with a relative with drug abuse problems, disorders with poorly controlled psychotic symptoms, or poor adherence to treatment (Al-Sawafi et al., 2021; Awad & Voruganti, 2008; Du Plessis et al., 2021; Kretchy et al., 2018).

In the emotional trajectory of family caregivers, emotions related to irritability were experienced almost exclusively in the past. In contrast, painful emotions and pressure appeared in both the past and present. On the other hand, emotions orientated towards coping and positive emotions were mainly identified in the present. However, when the relative faced a difficult time during the illness, the family caregiver reported painful emotions including fear, pressure and sorrow. These results suggest that as long as the caregivers accept the situation regarding the illness of their familiar and achieve adequate self-management developing coping strategies, their emotions are more positive. However, when the illness is not well controlled and the symptoms are exacerbated, the caregivers present more painful emotions. The study and follow-up of caregivers' negative emotions is crucial, as they could lead to pathological grief or depression (Olwit et al., 2015). The mental health of family caregivers of people with mental disorders should therefore be addressed by policymakers, and be one of the main goals for optimal caregiving (Brain et al., 2018; Díaz et al., 2020; Petrovic and Gaggioli, 2020; Zhao et al., 2019).

Our findings support other studies that identified that the caregivers' emotional trajectories were not static and did not follow a linear pattern (Marín-Maicas et al., 2021; Shiraishi & Reilly, 2019). A previous conceptual model on living with long-term conditions from the patient's (Ambrosio et al., 2015) and the family caregiver's perspective (Ambrosio et al., 2021; Marín-Maicas et al., 2021) described the experience of long-term conditions as a complex, cyclical and dynamic process that includes five attributes: acceptance; coping; self-management; integration and adjustment. In addition, several mechanisms such as changes in the patients' situation or personal circumstances, the existing social network and the perceived support or information could modify the process. The present study found that this emotional trajectory could change with the course of the illness, and the specific situation of the person with the mental illness may have a clear impact on it (Ambrosio et al., 2015; Marín-Maicas et al., 2021). Moreover, as in previous studies of caregivers of advanced cancer patients (Leow & Chan, 2017), the support received from other family members and friends and health professionals are critical for caregivers. Further research exploring the emotional trajectory of family caregivers and the different mechanisms or influencing factors should therefore be conducted to explain these aspects more in detail.

#### Limitations

This study has some limitations. First, the sample size is small despite enabling data saturation to be achieved. Second, the participants were selected from an organisation, and their profile might not represent all the family caregivers of people with mental disorders.

#### Implications for practice

These findings suggest the need for holistic and family-centred care, looking not only at the person affected by the disorder's needs but also at the family caregivers, as the latter could be affected by caring and this could influence their quality of life (Lima-Rodríguez et al., 2022). Current evidence suggests that there is a need for comprehensive policies that address the family caregivers of people with different long term conditions, such as mental health disorders. Interventions should include families to improve the process of living with a long-term condition from the family perspective, aiming at well-being and mental

health promotion (Årestedt et al., 2018; Kokorelias et al., 2019; Sarris et al., 2020; Ambrosio et al., 2021; Marín-Maicas et al., 2021).

More support from mental health services could help caregivers to progress in their emotional trajectory towards coping and improve their caregiving knowledge and skills. This support could positively impact their quality of life, and thus improve the quality of life of the people they care for (Lima-Rodríguez et al., 2022; Zhou et al., 2021). Mental health nurses have a role in patients' and caregivers' education and in the promotion of psychological wellbeing. This role consists of health education strategies, regular assessment, and professional referral, when appropriate.

## Conclusion

The past and present emotions related to caregiving described by experienced family caregivers were identified, and these were diverse: irritability; painful emotions including sorrow, nervousness, fear, uncertainty and loneliness in care; emotions towards coping, including acceptance and skepticism, and positive emotions including hope, calm and satisfaction. Their emotional trajectories converged in that negative emotions gave way to emotions focused towards coping, which in turn were followed by positive emotions. The participants' descriptions of their mental status were partially reflected through objective mental health measurements.

## Ethical statements

The Human Research Ethics Committee of the University of Valencia approved this research on September the 5th, 2019 (protocol number 1046761). Confidentiality of data was warranted and all the participants signed informed consent once they received all the needed information about the details of the study.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.apnu.2022.07.015>.

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