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# “Sustaining the burden”. A qualitative study on the emotional impact and social functioning of family caregivers of patients with psychosis

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## ABSTRACT

Evidence shows that caring for a family member with a psychotic disorder generates a significant emotional impact and repercussions on social functioning. However, this caregiving experience can be influenced by cultural factors. The aim of this study is to explore the experience and perception of a group of family caregivers of patients with psychotic disorders of different durations regarding the emotional and social functioning repercussions of caregiving on them in Andalusia.

Three focus groups (28 participants) were conducted. Data were subject to a thematic analysis. Three themes emerged from the data: 1) Emotional invasion; 2) Disruption in the caregiver’s life project; and 3) Changes in the family system. Participants reported experiencing sadness, fear, overwhelm, hopelessness, and uncertainty. Caregivers’ accounts reflected an interruption of their daily tasks, as well as the need to reformulate plans or goals outside the family life that require long-term commitment, such as professional development or even their residence. The narratives indicated an impact on all roles within the family system, particularly for the mother.

The results are consistent with existing research. Healthcare professionals and programs should take into account the costs associated with caregiving in order to minimize them, given the impact it has on both the patient’s and the caregivers’ health.

## Introduction

Since the emergence of community mental health, the care of patients with psychosis largely falls on informal caregivers (Lohrasbi et al., 2023). In a European study involving UK, Spain and Germany, it was observed that caring for people with schizophrenia or bipolar disorder occupied 38 weekly hours of support, with 20 % providing 50 h or more (Blanthorn-Hazell et al., 2018).

The concept of caregiver burden, defined by Dillehay and Sandys, refers to “a psychological state that ensues from the combination of physical work, emotional and social pressure, as well as the economic restrictions that arise from taking care of the patients” (Awad & Voruganti, 2008). This burden has been associated with a decrease in quality of life (Hayes et al., 2015), worse mental health (Hayes et al., 2015; Poon, Joubert, & Harvey, 2018; Sin et al., 2021) and physical health (Poon, Joubert, & Harvey, 2018), and poorer social functioning (Hayes et al., 2015). Influencing factors in caregivers’ burden have been reported such as demographic and social determinants (age, gender, educational level, income) or time dedicated to give support, competence on how to manage schizophrenia, as well as attitude and psychological stress (Sustrami et al., 2023).

Different emotional repercussions of caregiving have been reported, such as despair, devastation, fear, feelings of guilt, persistent worry, ambivalence towards certain dilemmas that arise (Estradé et al., 2023; Weimand et al., 2013) uncertainty (Estradé et al., 2023), high levels of psychological distress (Hayes et al., 2015; Poon, Joubert, & Harvey, 2018) or stigma, as well as a higher probability of having a mental disorder (Hayes et al., 2015).

Regarding social functioning, it has been observed that caregivers are more likely to be socially isolated (Hayes et al., 2015), engage in less paid work than non-caregivers (Bowman et al., 2014; Caqueo et al., 2017), and have more economic problems (Caqueo et al., 2017; Sustrami et al., 2023). In addition, high expressed emotion (EE), a pattern of family communication characterized by high criticism, overprotection, and hostility that has been shown to be a predictor of poor outcome in psychotic disorders, has been related to the level of distress associated

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with caregiving and social functioning (Gupta & Mohanty, 2016; O'Driscoll et al., 2019). Detecting and mitigating the role of these factors could contribute, therefore, to a reduction in EE and, consequently, a better outcome of the disorder.

Other factors such as the chronicity of care (Douki & Koutelekos., 2020), first episode psychosis (Kumar et al., 2019), a higher number of hospitalizations, lower educational level, or moments of greater symptomatic exacerbation (Blanthorn-Hazell et al., 2018) also contribute to a more negative caregiving experience (Sustrami et al., 2023). The healthcare system has a responsibility towards these caregivers, both for the repercussions it may have on the patient's outcome and the impact on the emotional well-being and quality of life of the family member. Therefore, healthcare programs and policies advocate for approaching the experience of caregivers and introducing measures in which caregivers are also, along with patients, a central part of psychosis healthcare (Awad & Voruganti, 2008; Poon, Curtis, et al., 2018; Sin et al., 2021; The Squizophrenia Comission, 2012).

Despite the gathered evidence regarding the emotional impact and social functioning repercussions that caregiving generates in family caregivers of patients with schizophrenia (Cleary et al., 2020; Issac et al., 2022; Shiraishi & Reilly, 2019), there are few studies that focus on the experience of family caregivers in Spain. The existing studies up to this point are quantitative studies focused on understanding the relationship between variables related to family caregiver burden (Blanthorn-Hazell et al., 2018; Ribé et al., 2018). Since the caregiving experience can be influenced by cultural factors (beliefs about health, coping strategies, available healthcare and community services…) (Tirupati & Padmavati, 2022), it becomes necessary to approach family caregivers in our context. Within Spain, healthcare services also vary from one region to another (Salvador-Carulla et al., 2010), potentially making the caregiving experience different among regions. Therefore, the aim of this study is to explore the experience and perception of a group of family caregivers of patients with psychotic disorders of different durations regarding the emotional and social functioning repercussions of caregiving on them in Andalusia.

## Method

### Study context and sample

A descriptive qualitative study was carried out at the Mental Health Service of the Regional University Hospital of Malaga (Spain), which serves a population of 165,000 inhabitants. Care services for persons with psychosis include acute hospitalization and specialized outpatient care in the community.

The study participants were selected by purposive sampling in accordance with the following criteria: to be a family member of a user diagnosed with a psychotic disorder (in the ICD-11 terminology, F20 Schizophrenia; F21 Schizotypal disorder; F22 Persistent delusional disorders, F23 Acute and transient psychotic disorder or F25 Schizoaffective disorder) and currently being monitored by the above Mental Health Service, and to be acting as the primary caregiver.

All those who fulfilled the inclusion criteria were telephoned to explain the objectives of the study and to request their participation. Those who were subsequently interviewed were again informed about the study goals, assured that all data would be treated in strict confidence and asked to sign the informed consent form. The sample size was determined in accordance with the principle of data saturation during data collection and analysis.

### Analyses

The study data were compiled from semi-structured interviews through focus groups. The unique segregation variable was that their family member was included in the hospital's first episode program, and therefore, the time since diagnosis was less than five years. The topics proposed to the participants were determined by the researchers on the basis of a prior literature review and by expert consensus (see Annex 1). The following topics were discussed: initial contact with the healthcare system, their involvement and engagement in healthcare offered to them, the range of interventions offered to them as caregivers, and the impact of their loved one's disorder on the family. The interviews lasted 90–120 min, and were carried out by a neutral interviewer, who was highly experienced in conducting qualitative interviews. Moreover, an observer took notes on the situation of each participant and the nonverbal aspects that might aid understanding of the interactions among participants. The interviews took place at a health center other than the one where usual care was provided.

All interviews were recorded and the audiotapes were transcribed verbatim, after which a content analysis was performed according to the principles suggested by Taylor et al. (2015). The transcripts were read to identify emerging themes, and were subsequently coded by a member of the research team. These codes were then triangulated, with reviews by two other members of the research team. Any differences in the codes proposed were discussed and resolved among the researchers. The codes were grouped into categories and subcategories, and analyzed taking into account potential researcher bias. All analyses were performed using ATLAS.ti (version 7, Berlin, Germany) software for qualitative data analysis.

The criteria of credibility, transferability, consistency and confirmability, as identified by Guba and Lincoln in this respect (Guba & Lincoln, 2000), were considered. To ensure the credibility of the analysis process, all codes and categories were triangulated. Transferability was strengthened by ensuring the completeness of data collection in each group, across multiple potential situations, scenarios and experiences with psychotic disorders. The criteria of data consistency and reproducibility were achieved by a detailed and documented description of the analysis process and the context in which data collection took place. With respect to assuring confirmability and reflexivity, before the start of the study, the researchers conducted an analysis of their own preconceptions and expectations regarding the study results, to consider the extent to which these might subsequently influence the study procedures. Additionally, the moderator/interviewer for the qualitative interviews was neutral (not a member of the research team) and was highly experienced in this field.

### Ethical aspects

All participants provided written informed consent to participate in the study. The Malaga Ethics and Research Committee approved this study. The principles of good practice and the provisions of the Declaration of Helsinki and its subsequent revisions were upheld throughout the study. The data were treated confidentially and pseudonymized for statistical analysis.

## Results

### Participant description

This study had 28 participants, distributed in four focus groups. The characteristics of the participants are specified in Table 1.

### Content analysis results

Three themes were identified regarding the consequences associated with caregiving: 1) Emotional storming; 2) Changes in the family roles and systems, and 3) Disruption in the caregiver's life project. In Table 2, the number of participants who mentioned each of the subtopics can be observed.

<u>1. Emotional storming</u>

1.1 "A blow to the head"

The family members interviewed, especially those with the most

**Table 1**
Characteristics of the participants.

| Participant | Age | Civil status | User relationship | User gender | User age | User civil status | User diagnosis | Age of onset of the disorder |
|---|---|---|---|---|---|---|---|---|
| 1 | 59 | Married | Husband | W | 57 | Married | Persistent delusional disorder | 37 |
| 2 | 68 | Widow | Mother | W | 42 | Single | Paranoid schizophrenia | 21 |
| 3 | 78 | Married | Father | W | 44 | Single | Paranoid schizophrenia | 18 |
| 4 | 54 | Single | Sister | W | 61 | Single | Paranoid schizophrenia | 34 |
| 5 | 46 | Married | Sister | W | 47 | Single | Paranoid schizophrenia | 37 |
| 6 | 60 | Widow | Mother | W | 47 | Single | Paranoid schizophrenia | 37 |
| 7 | 54 | Married | Father | W | 26 | Single | Schizoaffective disorder | 22 |
| 8 | 36 | Married | Sister | W | 50 | Divorced | Schizoaffective disorder | 35 |
| 9 | 73 | Divorced | Mother | W | 50 | Divorced | Schizoaffective disorder | 35 |
| 10 | 57 | Divorced | Mother | W | 29 | Single | Schizoaffective disorder | 25 |
| 11 | 49 | Married | Sister | M | 54 | Single | Paranoid schizophrenia | 18 |
| 12 | 79 | Married | Mother | M | 41 | Single | Persistent delusional disorder | 20 |
| 13 | 68 | Married | Mother | M | 39 | Single | Paranoid schizophrenia | 23 |
| 14 | 41 | Single | Sister | W | 38 | Single | Paranoid schizophrenia | 17 |
| 15 | 86 | Widow | Mother | M | 46 | Single | Simple schizophrenia | 29 |
| 16 | 74 | Married | Mother | W | 47 | Single | Paranoid schizophrenia | 34 |
| 17 | 86 | Widow | Mother | M | 54 | Single | Paranoid schizophrenia | 18 |
| 18 | 58 | Married | Mother | M | 27 | Single | Paranoid schizophrenia | 17 |
| 19 | 56 | Separated | Mother | M | 27 | Single | Paranoid schizophrenia | 20 |
| 20 | 62 | Married | Mother | W | 31 | Single | Paranoid schizophrenia | 23 |
| 21 | 56 | Married | Mother | M | 28 | Single | Paranoid schizophrenia | 19 |
| 22 | 59 | Married | Father | M | 20 | Single | Psychotic disorder* | 20 |
| 23 | 50 | Married | Mother | M | 24 | Single | Persistent delusional disorder* | 23 |
| 24 | 53 | Married | Mother | M | 19 | Single | Psychotic disorder* | 19 |
| 25 | 65 | Married | Mother | W | 23 | Single | Psychotic disorder* | 20 |
| 26 | 59 | Separated | Mother | M | 30 | Single | Psychotic disorder* | 29 |
| 27 | 51 | Separated | Father | M | 19 | Single | Psychotic disorder* | 19 |

*Note:* M = Man; W = Woman.

[*] Diagnosis proposed at the first months of health care and should be considered provisional.

**Table 2**
Frequency of participants who generated each subtheme. FG = focal group.

| Themes | Subthemes | FG1 | FG2 | FG3 | FG4 | Total (%) |
|---|---|---|---|---|---|---|
| Emotional storming | A blow to the head | 6 | 2 | 1 | 5 | 14 (50) |
| | After storm there is no calm | 2 | 5 | 4 | 5 | 16 (57) |
| | The crises | 4 | 2 | 4 | 3 | 13 (46) |
| Changes in family roles and system | The care becomes the center of life | 1 | 3 | 3 | 3 | 10 (36) |
| | Family roles | 3 | 2 | 2 | 2 | 9 (32) |
| Interruption in the family caregiver's life project | Loss of social networks | 0 | 2 | 2 | 3 | 7 (25) |
| | Job and economic losses | 0 | 0 | 1 | 1 | 2 (7) |
| | More severe consequences for the mother | 5 | 4 | 4 | 3 | 16 (57) |

recent experience of the diagnosis, recounted the emotional impact that the onset of the disorder had on them. Sadness, uncertainty, confusion or insecurity were some of the emotional experiences reported.

> *That's like a blow to the head, and you say, 'My God, what am I going to do now?' Cry, cry, cry, cry and cry. And it seems to me that today is the day when I cry the least.*
>
> *(Mother, 65)*

> *Restlessness, insecurity... and you end up there, thinking about that "package"... and you go to bed and all you do is think and think, and think... and you don't sleep!... but of course, it's your daughter... she's a young person... who has all the time ahead... and you say "how is she going to move forward?" And that... my wife is having a hard time with it... I also think she should go somewhere to sleep... because she works and when you stay three days without sleeping...*
>
> *(Father, 54)*

### 1.2 After the storm there is no calm

Multiple negative emotions coexist within the emotional experience of caregivers such as sadness, fear, anguish, confusion, or sorrow for the patient and the impact of the disorder on their life.

> *Then at home, imagine. All the windows closed. All the doors closed. At first, she would go into the shower with her robe and pijamas on because she was being watched, and you had to deal with undressing her... such a good girl. It's a shame that kills you. You say, 'But, my God, why? How could I have prevented this?'*
>
> *(Mother, 65)*

> *I know they need me a lot. Because even my younger daughter says to me: 'Mom, I'm not prepared for anything to happen to you'. Because she sees me with that anguish, and she says, 'I'm not prepared for anything to happen to you.' I say: 'You're already a grown-up.' She says: 'I'm grown up'. Because she's already 31, the youngest. The other one is 38. But the truth is, this is very hard. Very hard. Very hard.*
>
> *(Mother, 56)*

> *Very hard. The truth is that it was a very hard blow. I think it's a very difficult illness for her and for all the relatives around her.*
>
> *(Sister, 41)*

The feeling of overload or exhaustion and powerlessness is expressed by family members in the different interviews and on many occasions is associated with the situation of chronic care.

> *This is hard. It's not like a broken bone that heals over time...*
>
> *(Mother, 58)*

> *When all of this comes, you don't understand anything. In addition, there are enormous problems because everyone thinks something different (about how to approach the situations that are occurring) and it is very difficult to handle.*
>
> *(Mother, 68)*

> *I am older (...) and I am alone, as his father died 16 years ago, and there are three siblings. One is a professor in Cordoba, and the other is married and has just left, and I am alone with him. Alone, alone, alone.*
>
> *(Mother, 86)*

1.3 The crises

Some special circumstances that arise during the course of the disorder, such as hospitalizations or suicidal attempts by the patient, generate an increase in the suffering of the family members.

> *For me, the worst was when she was hospitalized... It was tough to see her there like that.*
>
> *(Mother, 73)*

> *When he was admitted, it was terrible, really, because I never imagined that four or five people would have to force him inside, because he kept saying he hadn't done anything... It was like he was fine one moment and not the next. And he would say 'I haven't killed anyone'. They left us outside, saying 'You can't come in from here, it's too hard.' But of course, we could hear our son screaming...*
>
> *(Mother, 59)*

> *My daughter was in bed for two years. And I was also scared because when she had been in bed for so long, one day she said to me 'Because I live on the first floor... If I didn't, I would jump.' Of course, all of that scares you.*
>
> *(Mother, 74)*

As a result of desperation, some family members confess to having even had thoughts of death.

> *I'm going to confess something. Sorry. When I came to see my son and I was leaving, I had to pass by one of the bridges... and after I came back from seeing him, I said "what if I jump? will it hurt? what will happen? and if I end up shattered, broken, overwhelmed? And my poor son, what will become of him?"; because I say it for the first time, but it was so much, so much, so much that I had on my mind*
>
> *(Mother, 59)*

> *And I feel very bad. Sometimes I think I want to die already because I can't take it anymore, because the pain I have with this girl is very big.*
>
> *(Mother, 62)*

> *I was very bad, crying and crying... crying all day, and "I would rather die than see her like this"*
>
> *(Mother, 73)*

2. Changes in family roles and systems

2.1. The care becomes the center of life.

Caring for a family member involves a reorganization of the daily routine for family members and, in many cases, a reorganization of their life project that places caregiving tasks at the center.

> *The problem is that... as I was telling him today: "Did you take your pill?", (son) "No." I say (...) I have to be aware of everything. I have a job. I travel, I... I don't have anyone...*
>
> *(Father, 51)*

> *In my case, the illness coincided with having a hyper-stressful job, and when I arrived home, there was the problem... Not sleeping at night... Waking up, waking up already with a problem... Going back to work... I arrived home very late at night... A thousand problems.*
>
> *(Father, 54)*

> *Last year, she (referring to her daughter) said: "Let's go... let's sign up for swimming!". Okay, let's go swimming. And we started going. Before 2 months she said to me: "I can't do it anymore". "You're not going anymore? But I signed up for you!" (....) It's incredible how she takes me to all these places, gets me hooked, and I have to go, and then she doesn't go.*
>
> *(Mother, 73)*

2.2. Family roles

Family relationships change, as well as the role that each member plays in the family. The onset of the disorder involves performing functions that do not correspond to their role and stage of life, for example, in the case of siblings, becoming caregivers while still young, or in the case of mothers, continuing to provide care that is typical of younger ages.

> *I've been doing it my whole life, day and night. We organized shifts. One day me, the next day someone else. My grandson, who was very young, has always been attentive to his mother. I tell him 'you've aged beyond your age!'*
>
> *(Mother, 73)*

It also requires readjustment by the patient's parents, who in many cases may have difficulty understanding the disorder and how to provide care.

> *In this time that my son has been like this, I was going to leave my husband twice because I think he spoils him too much, he is overly focused on him. I've told him many times that he hasn't accepted his son's illness.*
>
> *(Mother, 58)*

> *We were always arguing because he (referring to her husband) had one opinion and I had another. Besides, my son would say, 'I'm the 'no', and dad is the 'yes', and he would take advantage of that situation. But I thought about something: if I separate from my husband, what solution does that give me? Because I love my husband. I have a problem with my son, not with him. I can't change my husband. I can't change my son, but I can change myself. And it has worked for me, because I change and that's it. Because I am happy with him as my partner.*
>
> *(Mother, 58)*

Each member of the couple can learn to have different roles in providing care.

> *My husband supports me in everything and he is very attentive. And he has to... sometimes he has to be tough because I am weaker than he is. He can handle it with me.*
>
> *(Mother, 62)*

The situation also affects the siblings, causing a distance between them, or in some cases, requiring the non-diagnosed siblings to assume caregiving tasks.

> *His brother (her other son) used to live independently and he lost his home. And they moved into our home. But they hardly speak to each other now. They used to go everywhere together. They did everything together. They even did homework together.*
>
> *(Mother, 56)*

> *It's also very difficult when you start experiencing these problems as a child... I remember my other sister had to be taken out of the house because the situation was unbearable. My oldest sister had to take her away from the house. And I stayed behind and I remember thinking: 'when I can, I'll escape from here'. Then I left home very soon to get away. Later, I came back... because I understood the reality of what was happening, I understood that it was an illness, and that he wasn't like that just because he was like that, but because of his illness. So, almost all of us went through the same thing. At first, it was a stampede, everyone for*

> *themselves!... and then, when we all grew up and matured, we joined forces to help my mother pull through and move forward.*
>
> *(Sister, 49)*

> *(My daughter) is attached to me in such a way that she has a terrible fear that I will leave her.*
>
> *(Mother, 74)*

> *A three-person marriage... I go everywhere with my son. The three of us.*
>
> *(Mother, 68)*

### 3. Interruption in the family caregiver's life project

As a result of caregiving becoming the center of one's life, there is a review and reorganization of the caregiver's life plan, which is not always an easy task.

#### 3.1. Loss of social networks

The loss of social networks is also an aspect mentioned throughout the groups. This loss of social networks can be promoted by a rejection to talk about the disorder due to the stigma that it carries.

> *You see. It's hard for everyone. All illnesses are bad, but then there are others that are stigmatized, like this one. It's one of them. Why would I tell someone, "look, so-and-so, my son has this illness"? Well, no. Because so-and-so won't be able to help me in this aspect, so why bother?*
>
> *(Mother, 68)*

#### 3.2. Job and economic losses

In the following account, it can be seen how, in some cases, caregiving even involves having to leave work and the home where they lived.

> *The man who rented me the apartment said to me: "Your son slept on the street," because he was already having a breakdown... talking to the walls, talking to the plants... "And that scares us. You fix this today or you know what's going to happen, you're going to be on the street"; and my son slept on the street.*
>
> *(Mother, 59)*

> *I couldn't take it anymore, and my friend said to me, "Leave your job, resign... you can't be working and leaving him alone, resign, come live with me, and we'll see what to do with him." And that's what I did.*
>
> *(Mother, 59)*

#### 3.3. More severe consequences for the mother

In most cases, it is the mother who assumes the majority of the care, and therefore, experiences the most significant adaptation of her life project.

> *At a certain point in your life, you put everything on hold, your dreams, your projects. You dedicate yourself to that. But you do notice that it drags you down, isolates you, and you feel worse emotionally, and that can't be. When you have to be pulling someone else, you can't sink! That's when a little help is needed.*
>
> *(Mother, 57)*

> *I think what a mother or father does, siblings don't do.*
>
> *(Mother, 56)*

> *(...) well, the primary caregiver for my brother is not me. It's my mother, who is 84 years old. So, my mother has been a caregiver as long as I've known her. First, she was a caregiver when we were young. And then, when my brother was sick, she became the primary caregiver...*
>
> *(Sister, 49)*

> *As siblings, I think we practically didn't have to give up anything. It's my mother who has given up everything. Everything, because she's the one who takes care of everything from the beginning, and if there's a bad night, she's the one who deals with it, a bad answer, it's her, although later she has us on the phone, and we'll all be there in a second..., but she's the one who has given up her life for everything.*
>
> *(Sister, 49)*

> *My mother is completely dependent on her, and my sister is dependent on her... She has the support of my (other) sister and me, who know that if anything is needed, we are there because that is essential, but of course, she can't have the freedom to say, "well, now I'm going to go for a week with my sister in Madrid, and I'm with her." Of course, she can go, but we have to be there. It's not the absolute freedom she could have.*
>
> *(Sister, 46)*

Some relatives highlight the impact it has had on them, despite not being the primary caregiver. This impact in some cases involves early independence, a break with the diagnosed family member, and, in other cases, assuming care tasks, detection of possible symptoms and an intensification of support during crises.

> *The feeling was to say, "when I can, Ill run away from here". So, I immediately left home. (...). The same thing happened to almost all of us... At first, it was like a stampede, everyone for themselves!... And then, as we all grew up and matured, we did our best to help my mother cope with the situation and move forward.*
>
> *(Sister, 49)*

> *For example, now my sister was with my mother. She lived with my mother. But, I've been by her side a lot! Because my siblings were in Madrid, and I fought a lot, and it caught me very young, too... and I spent a long time not being myself.*
>
> *(Sister, 46)*

> *And the relapses are getting stronger, and they're affecting us as a family and me as a sister. My parents are older. So, I have to be behind her.*
>
> *(Sister, 41)*

In anticipation of the relief of care, care is assumed by another woman, in this case, the caregiver's daughters.

> *We have committed to her: 'Mom, don't worry, when you're not here, we'll continue taking care of him.' That's a huge relief for her! And it's what still keeps her going (...).*
>
> *(Sister, 49)*

## Discussion

The present study is an approach to the emotional consequences and social functioning that caregiving tasks entail for caregivers of family members with psychosis in Andalusian. Three categories are revealed: the first refers to the emotional impact that accompanies caregiving. The second shows the changes that the disorder generates in the family system and family roles, having repercussions on the subsystems of the couple and siblings, regardless of the role they play in caregiving. Finally, the third subcategory shows the reorganization of the caregiver's life plan in which caregiving occupies a central role.

A wide range of unpleasant emotions were narrated by the participants during the different moments of care. Emotions like sadness, fear, overwhelm, hopelessness, and uncertainty were identified in the participants' reports. The same emotional experiences were described by the participants in Landon et al.'s study (Landon et al., 2016). Specific situations such as hospitalization, episodes of agitation, the solitary experience of caregiving, professional support appear to be related, according to patients' accounts and previous research, to greater psychological distress or anxiety (Blanthorn-Hazell et al., 2018; Hickman et al., 2016; Ribé et al., 2018; Sin et al., 2021). These emotional experiences can remain as adaptive reactions to the situations experienced and therefore be functional, or they can become dysfunctional experiences compatible with mental disorders. Research focused on the study of the mental health of family caregivers of psychosis or schizophrenia has highlighted worse mental health, most commonly depression or anxiety disorders (Hayes et al., 2015), even greater than caregivers of people with other diseases (Sin et al., 2021). The thoughts of death in the interviewed caregivers reflect the suffering involved in caregiving. Previous research also found the emergence of these thoughts among caregivers of individuals with chronic illnesses, both physical (Czeisler et al., 2021; Margolis et al., 2023; Solimando et al., 2022; Zwar et al., 2023) and psychiatric (Avci et al., 2021; Corchón et al., 2022). An important difference between psychotic disorders and other illnesses is that caregiving, in most cases, outlives the caregiver. Anticipatory distress could increase caregiver stress and, therefore, the emergence of suicidal thoughts as a means of seeking relief. Healthcare services should, therefore, take this risk into account and provide the necessary support to ensure the caregivers' well-being.

Regarding the changes that caregiving generates in the family system and family roles, the narratives indicate an impact on all roles within the family system. Family breakdown (Shiraishi & Reilly, 2019), the challenge of caring for other family members who also require assistance (Kumar et al., 2019), and changes in marital relationships (Young et al., 2019) are some of the changes that qualitative research has highlighted. The interviewed sisters reflected that the disorder had the greatest impact on their mother, although these results are not consistent in previous studies (Kumar et al., 2019; Rahmani et al., 2022). However, the so-called "sandwich caregivers," sisters who end up assuming the care of both their dependent siblings and parents, as can be inferred from the participants' discourse during the focus groups, should also be taken into account by the healthcare system (Centre for Policy on Ageing, 2015). Sibling caregivers, especially sisters, exhibited poor mental health, negative caregiving appraisals similar to those of parent caregivers, as well as distinct and overlapping needs (Sin et al., 2016). The perception of the severity of the sibling's symptoms and the frequency of treatment predicted the "conflict" dimension of the relationship with the diagnosed sibling (Plessis et al., 2020). Coping styles also differed based on the type of relationship with the diagnosed individual, with emotion-focused coping and seeking social support prevailing among sibling caregivers (Plessis et al., 2022). These findings make it necessary to include siblings in intervention programs, which, on the other hand, have proven to be useful for both the patient and the family (Bowman et al., 2014).

Finally, regarding the reorganization of the life plan, the caregivers' accounts reflect an interruption of the caregiver's daily tasks, as well as the reformulation of plans or goals outside the family life and that require long-term commitment, such as professional development. For caregivers, this involves making decisions regarding their career or even their residence. These decisions imply financial difficulties and negative effects on work indicated by previous studies (Bowman et al., 2014; Caqueo et al., 2017; Kumar et al., 2019). Most of the interviewees were women, and among these, most were the users' mothers. The second largest group was the sisters. The tendency for a woman to take care prioritizing it over other areas of her life is a reflection of gender role socialization (Puzio & Valshtein, 2022) and is, therefore, also reflected in the study. Social relationships are also affected by caregiving according to the interviewees' accounts, often resulting in situations of social isolation (Hayes et al., 2015) or conflicts in interpersonal relationships (Shiraishi & Reilly, 2019). Hayes et al. (2015) concluded that caregivers of patients with schizophrenia are 10 times more likely to be isolated. This isolation is also related to worse mental health for caregivers, quality of life, a sense of burden (Hayes et al., 2015; Ribé et al., 2018; Sin et al., 2021), and high expressed emotion (Gupta & Mohanty, 2016). Regarding the causes, some participants mentioned stigma. The literature shows that among the consequences of stigma on the social functioning of family members are isolation and fear of rejection, among others (Hussain et al., 2024; Serrao et al., 2023).

The results of this study allow us to identify the emotional and social difficulties that family caregivers of individuals diagnosed with psychoses. The practical implications of these findings are directed towards both healthcare professionals and programs, as well as towards family members who are in a caregiving situation similar to that of the study participants. On one hand, professionals need to address the costs associated with caregiving and provide support and interventions that minimize this burden, given the impact it has on both the patient's and the caregivers' health. Psychiatric nurses are the main reference providers for caregivers during many phases of the process, so that these finding should be taken into account from their first assessments of the dyad patient-caregiver. On the other hand, family caregivers in a similar caregiving situation can find validation of their experience in this study, a reaffirmation of the strategies they already use, and the opportunity to learn new ones.

Finally, it's important to view these findings in light of certain limitations. Firstly, there may have been some self-selection bias, as the analysis only considered caregivers who agreed to participate in the focus group. It's possible that this decision may have been influenced by the level of satisfaction with the healthcare they received. Secondly, all participants were treated in the same health district, which could compromise the generalizability of the results obtained.

## Conclusion

This study provides an insight into the emotional and relational experience of family caregivers of patients with psychotic disorders. The interviewees, mostly women and mothers, report a high negative emotional impact associated with the caregiving experience, along with an impact on their life plans and the family system. The importance of this study lies in the need for the family to be at the center of healthcare, alongside the patient, given the repercussions that these reported experiences can have on both the quality of care and the patient's evolution, as well as the caregiver's own well-being and health. Raising awareness of this experience can help the healthcare system to identify current needs and, therefore, implement measures aimed at meeting them.

Supplementary data to this article can be found online at https://doi.org/10.1016/j.apnu.2024.05.015.

## Ethical statements

The study was conducted in accordance with the Declaration of Helsinki, and approved by the Provincial Ethics Committee of Malaga (Date of approval: 29 March 2016).

Informed consent was obtained from all subjects involved in the study.

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## CRediT authorship contribution statement

**Amelia Villena Jimena:** Conceptualization, Data curation, Formal analysis, Investigation, Validation, Writing – original draft, Writing – review & editing. **José Miguel Morales-Asencio:** Conceptualization, Formal analysis, Methodology, Supervision, Validation, Writing – original draft, Writing – review & editing. **Casta Quemada:** Data curation, Investigation, Resources, Validation, Writing – original draft. **María M. Hurtado:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

## Declaration of competing interest

During the preparation of this work the authors ChatGPT in order to help to traduce. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

## Data availability

Data will be made available on reasonable request.

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