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# Exploring mental health carers' caregiving experiences in France

Nancy de Jesus , Aurelie Maurice

## 1 Introduction

In France, as in other parts of the world, the paradigm of psychiatric care is shifting from a costly care institution (the hospital) to a “low-cost institution” (the family). According to the literature, this transition extends far beyond the field of psychiatry and has become a societal issue (Morin, 2012). Today, not only is the French government faced with an aging population; it must also handle the increasing number of chronic diseases that disrupt the public health system and family dynamics. The composition of the French family is also undergoing fundamental changes as sibling sizes fall, divorce cases increase, single, step-parent or blended families expand and more women engage in professional work. (Davtian & Scelles, 2013).

Consequently, a crisis has emerged regarding the caregiving role of French carers. While health professionals attend to a patient's body, the family is entrusted with the unlimited task of free “daily care”, as stipulated in France's 2011-2015 Psychiatry and Mental Health Plan. While the French family's composition is undergoing significant changes, it is also faced with increased responsibilities, the latter of which have become harder to handle due to a challenging context and to the pressures faced by the public health and social care systems.

Such a role is not easy to endorse. A French action research, MHGP<sup>1</sup> (Caria et al, 2010) highlighted the overwhelming representation of insanity and “mental illness”<sup>2</sup> in the French general population (this study conducted on 36,000

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<sup>1</sup> Mental Health in General Population: Images and realities

<sup>2</sup> We have chosen this term to be consistent with the most widespread representation of psychiatric disorders in France. As highlighted above, there is an overwhelming negative representation of mental health in the general population in France. In this study, we used “mentally-ill” as a common term to designate a person with a range of medical conditions (such as major depression, schizophrenia, obsessive-compulsive disorder, or panic disorder...) to relate with the current image of mental health in France.

persons from 47 French public institutions). Moreover, according to a population survey on the attitudes and beliefs of the French public on “mental illness” (Angermeyer *et al*, 2013), educational programs are greatly needed to reduce existing misconceptions and to improve mental health care in France.

In this study, we therefore chose to focus on the caregiving experiences of French mental health carers. The first objective was to identify the carers’ representations of “mental illness”, their difficulties and their needs when caring for their “mentally-ill” relative. The second objective was to transform our findings into an educational program that would focus on carer empowerment and on supporting positive relationships within the family.

#### Family caregiving in mental health in France and abroad

In 2000, the WHO<sup>3</sup> described the need to consider families as part of the health care process. There was therefore a need to take a better interest in families and train them in psychiatry. Families began to organize into associations globally through the NAMI<sup>4</sup> in the United States, the FFAPAMM<sup>5</sup> in Quebec, the UEFAMI<sup>6</sup> in Europe and the UNAFAM<sup>7</sup> in France.

Since its creation, the UNAFAM has offered information and training to support the carers of persons with mental disorders. Some of the courses on offer are: “Information day on mental disorders”, “*Prospect*” which is a self-help workshop, “*Post-Prospect* day” and “Communicating Better with Your Bipolar Relative”.

In France, the reference program for the psychoeducation of families is PROFAMILLE<sup>8</sup>. Its objectives are to train families about “mental illness” and its management. It also aims to provide better coping techniques such as stress management, strengthening communication skills and problem-solving. One of the program’s major goals is to provide useful documents on the

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<sup>3</sup> World Health Organisation

<sup>4</sup> National Alliance in Mental Illness

<sup>5</sup> *Fédération des Familles et Amis de la Personne Atteinte de Maladie Mentale*

<sup>6</sup> European Federation of Families of People with Mental Illness

<sup>7</sup> *Union Nationale des Amis et Familles de Malades Mentaux*

<sup>8</sup> *Programme de formation des familles*

(de)stigmatisation of mental illness (studies, reports, news articles) in France and abroad to patients and their families. Such information is essential to improve results since patients and carers who experience stigma are far more likely to have negative outcomes.

By organising families into associations and offering programs for families, these two movements can be viewed as the consequence of care spilling outside of the hospital and as an attempt to respond to the current paradigm of psychiatric care. According to a recently published book, "*Psychiatrie: l'état d'urgence*," this situation is worrying. This book was the first to survey French psychiatry and its scandals, as France's mental health system is currently sinking in the face of major challenges when caring for 12 million patients; the piece presents the critical point of view of carers and health professionals (Leboyer and Llorca, 2018).

International published literature has indicated the existence of various government subsidies and support programs such as family therapy on respite care, rehabilitation and mediation when coping with caregiving burdens and home visits. Such programmes devoted to mental health carers are almost non-existent in France but are common in countries like the US, Canada, Australia and the UK (OECD<sup>9</sup> 2011). In the UK, "Crossroads Care" has been an advocate for families since 1974 by offering a range of individually tailored support and group activities.

In France, domiciliary visits only represent 17% of eligible patients with mental conditions (Verdoux, 2007); surprisingly, we were unable to find data on the in-home visits of French carers. Moreover, in the French psychiatric hospital setting, aside from occasional symposiums, individual interventions and compensations for carers are almost non-existent, unlike in France's Western counterparts, as mentioned above. According to Médiaprisim (2016), 75% of families support their sick loved-one on a daily basis and the hospitalisations of these relatives with mental conditions are painful experiences. Furthermore, as

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<sup>9</sup> Organisation for Economic Co-operation and Development

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reported by the C4C<sup>10</sup> Survey France, 93% of carers in mental health are not given much information and support about their role as caregivers. “The greatest need of carers lies in the recognition that they can be a full partner in care, but they need to be listened to and taken seriously by health professionals” (Vermeulen et al, 2015).

Thousands of research articles about family carers have been published in other countries. And yet, to our knowledge, only a few investigations on French mental health carers have been published to this day.

Several countries, including Australia, Sweden and the United Kingdom, have already developed protocols to assess the needs of carers in appropriate ways. According to the OECD, mandates for carer assessment are rare, except in the UK; this often results in a lack of resources and prevents the implementation of systematic evaluations. Therefore, “Exploring mental health carers’ caregiving experiences in France” is a first step towards defining the services that need to be implemented in France. It provides essential data to aid both professionals and policymakers at the local, national and international levels to offer more support for carers in mental health.

In view of these circumstances and due to the increasing number of mental health carers – more than 3 million people, or 4% of the entire French population (WHO-France, UNAFAM, 2017) – this study poses the following question: How can carers in France be supported as they provide caregiving assistance to a mentally-ill relative?

**2 Method**

**2.1 Research design**

This qualitative research study was conducted in 23 months; from January 2018 to November 2019. It consisted of in-depth semi-structured interviews with

<sup>10</sup> Caring for Carers Survey France

carers or “caring family members” of persons with mental health disorders in France. The inclusion criteria were defined to the participants as carers or “caring family members” who provided emotional, financial and practical support, such as cooking or assisting in any household chores and medical appointments. The exclusion criteria were based on the frequency of the support given, which had to be daily assistance. The criteria were determined so as to obtain the most realistic and generalised external validity of caregiving experiences to patients with mental disorders, as relevant to the carer population in France.

## 2.2 Participants selection

French carers were recruited through the UNAFAM - Greater Paris Area during meetings, conferences and forums. All participants were in frequent contact with, and cared for, a family member who had been admitted several times in psychiatric care in a French clinic or hospital over the course of several years.

## 2.3 Study sample

This research included 15 unpaid French carers of patients diagnosed with mental health conditions (see Table1). Eleven of the participants were women and four were men, all of them were French nationals born in France. Their ages ranged from 19 to 82 years. While three of the participants were already retired, ten adults were still working, one carer was unemployed, and another carer was a student.

**Table 1: French carers’ attributes**

Name <sup>11</sup>	Gender	Age	Profession	Relationship to the “mentally-ill” patient
Francine	F	75	retired	mother of a schizophrenic patient
Jeanne	F	68	retired	mother of a schizophrenic patient

<sup>11</sup> To respect anonymity, the names of all the people questioned have been modified.

Vivienne	F	50	unemployed	daughter of an Alzheimer's patient / sister of a schizophrenic patient
Claude	F	82	retired	mother of a depressive psychotic patient
Angel	M	19	student	son of a chronically depressed patient
Anne	F	55	employed	sister of a bipolar patient
Yasmine	F	40	employed	sister of a bipolar and a schizophrenic patient / aunt of a bipolar patient
Olivia	F	42	employed	step-sister of a schizophrenic patient
Pierre	M	48	employed	brother of a bipolar-schizophrenic patient
Beatrice	F	48	employed	daughter of a paranoid-schizophrenic patient
Dianne	F	51	employed	aunt of a chronically depressed patient
Helene	F	55	employed	mother of a bipolar patient
Laure	F	45	employed	wife of a post-traumatic stress patient
Eugene	M	49	employed	husband of a bipolar patient
Robert	M	50	employed	father of a mentally disabled patient (undisclosed condition)

## 2.4 Interview tool:

We used a semi-structured interview guide in French to conduct the interviews (see Table 2). Each interview started with the request "Tell me about your caregiving experiences," thus allowing participants to determine the direction of the conversation.



**Table 2: Interview Guide**

1. Tell me about your caregiving experiences...
2. Can you please introduce yourself?
3. How's your relationship with your sick relative?
4. Are there times when your relationship with the patient becomes difficult?
5. What difficulties do you encounter?
6. What does "mental illness" mean to you?
7. How do you establish a positive relationship with the patient?
8. What role do you think family & friends have when caring for a "mentally-ill" person?
9. In your opinion, how can families be helped in their difficulties when caregiving for a relative with "mental illness"?
10. Are there other themes that you would like to discuss?

## **2.5 Description of the interviewing process and ethical considerations**

The interviewer, Author 1, assumed an open stance towards the participants: this meant that, aside from occasional prompts from the interviewer, the carers were the ones handling the flow of the interview. The French carers who participated were told about the study and were aware that their answers would be used in the context of scientific research and that anonymity would be respected. Informed consent was subsequently considered as given when the participants agreed to complete the recorded interviews.

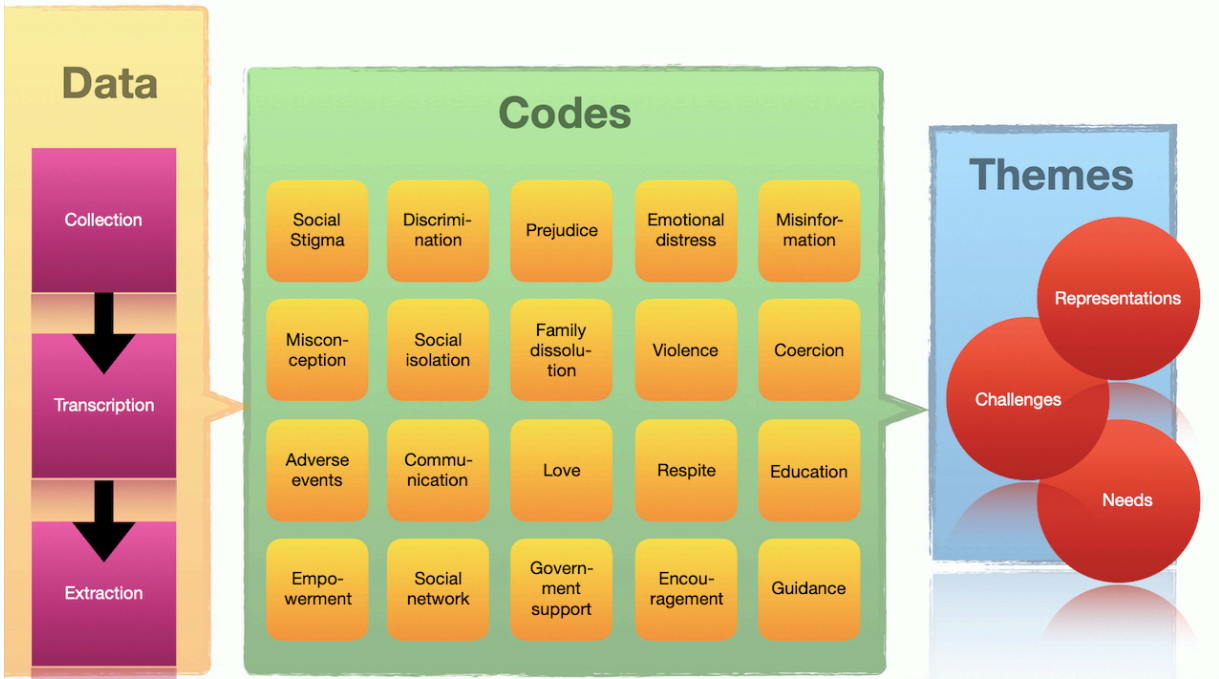
## **2.6 Analytical process**

All interviews were digitally recorded and transcribed in French. The gathered findings were then analysed in French and translated into English. First, the data was read carefully to identify texts that were relevant to the research topic. Second, we grouped the texts in which the same issues were described into analytic categories. Some texts were included in more than one category. Third, the data was systematically reviewed to ensure that all interviews had been identified. During the entire coding process, memo writing was used as an analytical tool and as a means of reflection. Both the data and memos were shared with Author 1's research director

(Author 2). These were discussed until a consensus was reached.

The data was analysed using the inductive thematic analysis procedure (see Figure 1), a comprehensive process where the researcher identifies numerous cross-references in the data and compares them with evidence pertaining to different situations in the evolving objectives of the research (Hayes, 1997). Due to the interviews’ unique focus on French carers, we used an inductive approach to identify the themes that were strongly linked to the study’s objectives. According to Braun and Clarke (p. 82), a theme is a category “that captures something important about the data in relation to the research question”; it emerges when a high degree of convergence is found between the various participants’ experiences. Consequently, relevant literature was reviewed before and after the analysis was completed.

**Figure 1:** Inductive thematic analysis of mental health carers’ caregiving experiences in France



### 3 Results

Below are excerpts of interviews given by French carers about their personal experiences when caring for a “mentally-ill” relative. The inductive thematic analysis resulted in several categories with the emergence of three general themes: the carers’ representations of “mental illness”, their encountered challenges and their caregiving needs.

#### 3.1 French carers’ representations of “mental illness”

##### Social-stigma, discrimination and prejudice

These are some of the stereotypes that persons with “mental illnesses” and their families endure in French society: A father-carer, Robert, shared: *“It’s difficult to explain his mental disability to others ... people on the street give us an indifferent look.”* Olivia, a step-sister carer, expressed intense feelings of rejection against “mental illness”: *“All siblings rejected my step-brother. We think, he’s a sick person! Crazy! Aggressive! that’s negative!”* All interviewed carers conveyed that “mental illness” was often unappreciated and that reticence and intolerance pervaded the attitudes and beliefs of French society toward psychiatric diseases.

##### Emotional distress

Negative feelings of hurt, fear, doubt and frustration were expressed by all participating carers. For a mother-carer, Claude: *“As a disease, I find that it’s difficult to bear... Like a sword of Damocles above your head. When things are going well, we wait for it to get worse. And then when it goes wrong, we wait for it to be better...”* Uncertainty was one of the main concerns among parent-carers. They stressed the fact that France did not have enough institutions nor trained professionals in mental health.

##### Misinformation and misconception

Sibling-carers addressed several unanswered questions. Anne, a sister-carer, said: *“mental illness” is often badly depicted on tv... but I didn’t know exactly what it was and when you don’t know you’re afraid. I don’t know... Is it contagious? Is it treatable? What should be done?”* While a brother-

carer, Pierre, expressed the following: *"For me, it's someone who doesn't have a brain... nothing makes sense to my brother. It's the worst disease."*

As the interviewed carers reported, the brutal media coverage of mental health disorders contributes to its negation among the French general population. Perceptions can be altered through repetitive negative and imprecise portrayals in the media and on the Internet, thus worsening the issue of "mental illness".

### Social isolation

Most carers described feelings of inner suffering and discomfort. A young-carer, Angel, grieved for the father he once knew: *"It hurts a lot... I felt orphaned, some relatives have stopped coming to the house... but I always hoped my father, the one who's not sick, would come back..."* Most participants described their isolation as the absence of normal social networks: They stayed at home for long periods of time, they did not have access to services or community involvement, and they rarely communicated with friends, family and acquaintances.

## 3.2 French carers' caregiving challenges

### Family dissolution, violence or coercion

Some carers experienced conflicts that resulted in receding relationships with their families. Pierre, a brother-carer, shared: *"We can't handle my brother's craziness because he doesn't take his medications... One time, during a mental breakdown, he destroyed at least 10 cars... [...] Sometimes I have no choice... I prefer him to sleep in prison... than to be slaughtered by street people!"* Olivia, who is a carer and a member of the patient's extended family, angrily spoke about the deterioration of her marriage and of other family relationships: *"It's catastrophic! My brother-in-law won't let us sleep at night!... He screams insults... in front of the children, in front of everyone and I'm sick of this situation. That's why I told my husband... This time, it's either me or his brother!"* Based on the verbatim statements, it seemed harder for the people who were not blood relatives to bear such caregiving situations.

### Incomprehension of adverse events

This was highlighted by all participants: all carers expressed their confusion and bewilderment when their loved-ones faced critical situations. Francine shared: *"My son accused us of poisoning him. Whenever he had auditory hallucinations, he gave us an extraordinary atmosphere at home... One time he wanted to attack his grandmother. He insulted her because he was convinced... that she had called him a bastard! It took me a while to understand that!"* These adverse events stretch the inner dynamics of the family to the limit. A husband-carer, Eugene said: *"I didn't understand why she made exorbitant purchases and it's me who had a hard time getting our money back..."* It can also be observed that most carers continued being caregivers in spite of their predicaments; some expressed notions of acceptance despite their personal difficulties.

### Loss of the patient's identity

However, some participants mentioned that, during a mental crisis, the shift in their loved-ones' normal selves added to their frustrations. This inability to perceive a person's identity led to tensions: mother-carers found it difficult to care for someone they barely recognized. Claude, a mother-carer, stated: *"When she's in crisis it's extremely difficult! I don't recognise my daughter! That's not her! Because my daughter is very kind, very tolerant... but there, it's like she's another person... She rejects me!"* A young-carer, Angel, sadly explained: *"He was full of love for us. But a few days before his first hospitalisation, he was always angry. He changed since... Normally, parents look after their children... Now, it's tough to keep a relationship with someone who's depressed and pessimistic... it's exhausting and I miss my father..."* This verbatim shows that one of the consequences of a parent's "mental illness" is the inversion of roles. Family members have difficulties adapting to the new dynamic, sometimes to the point of putting the relationship at risk. Likewise, data results confirmed that children felt awkwardness and grieved the parent they once knew.



### Communication withdrawal

Communication is essential in all relationships. The carers who were interviewed talked about the challenges associated with the inability to interact with family members. According to a sister-carer, Yasmine: *"We have communication problems... my brother has interpretive tendencies. Sometimes we don't understand what he says... or he cuts us off... but the real problem is, we can't comprehend his world!"* Robert, a father-carer, said: *"My son is non-verbal. He screams and slaps when he is frustrated, tired, anxious and manifests violently..."* Carers indicated that ineffective verbal or non-verbal communication and challenging behaviours were consequences of "mental illness" that further strained family relationships. These constituted the greatest number of difficulties and were highlighted by all participants.

### Feelings of love and respite

Most French carers conveyed their hope and eagerness to face "mental illness" with a positive attitude and with the right emotional distance. Robert, a father-carer shared: *"Being sensitive to the needs of our son can be enriching... but there are constraints: we can't receive guests and we can't get out much..."* A daughter-carer, Beatrice, advised: *"By meeting a psychologist, I was able to speak out what's in my head... I learned to accept that my father can't be cured... In fact, what's left in our family is love... and it helped to maintain a link..."* These carers shared different positive coping skills and respite techniques when dealing with the burden of "mental illness". They suggested seeking professional support, finding information and accepting their loved-ones' disease.

## 3.3 French carers' caregiving needs

### Mental health education and carer empowerment

To lessen the burden of caregiving, all interviewed carers acknowledged their critical need for training. Anne, a sister-carer, declared: *"If we are informed a little more... and if we are not left out... because they (professionals) often forget that those around the patient also suffer... I don't know*

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3 *"mental illness". It's still taboo, and we don't have much information."*  
4 Eugene, a husband-carer, said: *"I would like to learn more about the*  
5 *illness, treatments or support for my wife, because obviously, my children*  
6 *and I have no choice..."* Claude, a mother-carer, shared: *"I think we're*  
7 *powerless. I feel helpless, doctors don't even want to hear from the*  
8 *parents..."* All participants needed more information, but they felt  
9 neglected, excluded or not valued by French healthcare professionals.  
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### 17 Social network

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19 Most participants expressed the importance of connections allowing them to  
20 share and learn about mental health. In the following verbatim, a brother-  
21 carer, Pierre exclaimed: *"The hospital, they do nothing for the families... they*  
22 *won't listen to us... we can't even go see them... Do we have to*  
23 *punch our fists, shout or get sick like real psychotic people to be heard?*  
24 *Even at the town hall, I asked for help... they gave me a list of*  
25 *associations... that's all! We don't know of any other structures for*  
26 *families!"*  
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### 35 Government support

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37 An aunt-carer, Dianne, reported that *"Carers can't do it alone."* A sister-carer,  
38 Yasmine expressed: *"We need prevention and massive information*  
39 *campaigns."* While Olivia, a step-sister carer, insisted: *"The hospital isn't*  
40 *enough. We really need a boost from the state."* Robert, a father-carer,  
41 suggested: *"The government must open more structures and train more*  
42 *professionals..."* These carers offered the view that the French  
43 government had to do more to promote "mental illness". Unfortunately,  
44 this is a current dilemma in French society since there is an inadequate  
45 amount of skilled mental health staff and appropriate structures.  
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### 54 Encouragement and guidance

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56 Some carers were apprehensive and asked for external supervision. Vivienne,  
57 who cared for her sick brother and her aging mother, asked: *"Who can*  
58 *help me and tell me why mom reacts like that? I do everything instinctively*  
59 *and without ever being sure..."* A young-carer, Angel, offered:  
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3 *“Caregiving... I think it takes a lot of patience and love... we need advice*  
4 *from those who understand the disease. Am I going to be sick as well?*  
5 *But first, I would like to know how to ease my father's suffering or how to*  
6 *make him happy... to hear that he'll be okay. Rather than searching on the*  
7 *internet... with my mother and my little brother we try to get by... But we*  
8 *don't know if we're doing it right or not.”* The participants of our study  
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10 were in need of close support from people who shared similar  
11 experiences; could peer support be an answer?  
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## 21 **4 Discussion**

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24 Participants revealed their vulnerabilities when caring for their “mentally-ill”  
25 relatives. At different moments, more negative emotions were expressed than  
26 positive ones. The French carers’ testimonies demonstrated that family  
27 interventions should focus on the pursuit of information in which “mental illness”  
28 was more positively represented (the sub-themes of negative representations  
29 were: social stigma, discrimination, prejudice, emotional distress, misinformation,  
30 misconceptions and social isolation). Secondly, French mental health carers  
31 encounter constant challenges and stress as caregivers (cited predicaments  
32 were: family dissolution, violence or coercion, incomprehension of adverse  
33 events, loss of the patient’s identity and communication withdrawal). Third, but  
34 not least, the French carers who were interviewed expressed their need to  
35 develop personal strengths (through coping strategies, respite, educational  
36 support, empowerment, social networks, government support, encouragement  
37 and guidance). French carers in mental health should therefore benefit from  
38 appropriate educational programs, from the support of health professionals and  
39 from French government assistance.  
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### 52 **4.1 Correlation between data findings and the literature**

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55 The singularity of this research lies in the rare individual interviews that provide  
56 us with the first-hand testimonies and personal experiences of mental  
57 health carers in France. Despite the small scale of the recruited sample,  
58 this study’s data set included carers who had different types of  
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relationships with individuals suffering from mental disorders. A range of psychiatric diagnoses, ages and living arrangements with family carers were represented. Despite these differences, the accounts of the French carers resonated with each other and with the results of other qualitative studies as follows.

What emerged from the first theme of this study were the carers' negative representations of "mental illness" which altered family relationships and consequently affected the carers' roles and behaviours towards their "sick" family member. These findings further validated the overwhelming prejudicial representations of "mental illness" within France's general population (Durand-Zaleski *et al* 2012.) In retrospect, although France was a pioneer in psychiatry as early as the eighteenth century, its current progress in mental health matters has stalled. The stigma surrounding "mental illness" is still an important societal problem. The general population seems to be largely ignorant of this problem and the fear of the "mentally-ill" remains prevalent. While "mental patients" are no longer burned or killed as they were in ancient times, French social standards and attitudes are nonetheless unworthy of the standards of modern welfare states. Data has proven that stigma, discrimination and prejudice towards the "mentally-ill" and their carers are still pervasive, both in the context of French legislation and of rehabilitation efforts.

With reference to the second theme, each participant expressed their perceived stressors. The French carers' burdens were amplified as they expressed appalling difficulties caring for their ill relatives on a daily basis. Like the aforementioned negative representations, the consequences of these difficulties affected their relationships negatively and worsened the inner workings of their families. Data results proved that high subjective burdens had an overall impact; they included the carers' incomprehension of "mental illness" and communication withdrawals towards their sick loved-ones. These were the greatest number of difficulties, as highlighted by all participants. According to Gilbert *et al* (2008) finding ways to promote effective family communication such as listening, talking and

understanding, may help a family adapt more positively to mental disorder; the importance of communicating within the family unit, despite the mental crises, was highlighted. Thus, better understanding precedes better communication and generates positive relationships. For positive family interactions to occur, a carer must also be adequately informed on mental health, he/she must be approachable and initiate communication with the “mentally-ill” relative. But to do so, carers also need protective coping strategies.

Regarding the third theme, the French carers shared their caregiving needs and various coping techniques. As defined in the literature, coping is the family’s ability to redefine stressful events and make them more manageable (Young 1995). While some carers expressed positive feelings towards their “sick” relatives, the participants described various caregiving stressors as barriers to family interactions. As explained in the literature, two categories of stressors apply to the process of coping with “mental illness”: the normative stressors involve transitions in life cycles, as family relationships change; the catastrophic stressors, such as shame, embarrassment or stigma, strike families suddenly and often overwhelm their ability to cope (McCubbin *et al*, 2001).

While this study explored the caregiving experiences of French carers in mental health, and while the interviews affirmed their vulnerabilities, carers also want to be included in the French government’s response to this growing societal issue. Hence, health professionals should be promptly trained to handle and provide quality support for carers.

#### 4.2 Possible areas of improvement

Our results helped us to reflect on proposals for educational programs aimed at French mental health carers. Out of the collected data, one of the most important findings was that the participants often mentioned the context of the first hospitalisation of their “mentally-ill” relative when they talked about their caregiving experience. This may be due to the fact that carers felt apprehension, guilt or conflict when they thought of such a hospital

1 stay. As proven by the interviews, all of the French participants – and the  
2 young carers in particular – referred to this moment as a painful traumatic  
3 experience which they could not get out of their minds. The data also  
4 showed that this was a period of heightened stress and that the carers  
5 needed explanations and support from health professionals. According to  
6 the EUFAMI, the relationship between families and mental health  
7 professionals differs in Eastern European countries as families have  
8 never been excluded from the treatment process. However, none of the  
9 French participants mentioned feeling recognised in their caregiving role;  
10 instead, they felt excluded from treatment and care plans. French mental  
11 health professionals may not have acquired the skills of working with  
12 families due to their training stressing the need to maintain confidentiality.  
13 In French health culture, excluding carers may be equated with a patient's  
14 right to have a confidential relationship with his/her doctor. Also, it is  
15 important to add that, due to reduced public health budgets, French  
16 psychiatry is currently facing a structural crisis which implies the  
17 reshuffling of health professionals (Verdoux 2007.) Furthermore, the  
18 numerous French government national programs that aimed to  
19 renovate France's mental health services have not yet kept their promises  
20 (IRDES<sup>12</sup>, 2014). Unfortunately, most of the French carers who were  
21 interviewed condemned the fact that some professionals still avoided  
22 speaking to the families.

#### 4.3 Educational program

23 A stay in a French psychiatric ward lasts an average of 53 days per year while  
24 home hospitalisations can last 3 months, as reported by the DREES<sup>13</sup>  
25 (2012.) During this period, individual orientations take place for French  
26 psychiatric patients as they enter inpatient programs. However, data  
27 results did not indicate that families were instructed on operating  
28 principles and psychiatric care procedures, even though international  
29 studies have shown that early intervention programs improve clinical and  
30 social outcomes for both patients and carers. Data revealed that

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<sup>12</sup> Institut de recherche et de documentation en économie de la santé

<sup>13</sup> Direction de la recherche, des études, de l'évaluation et des statistiques

powerless French carers sometimes turned to associations for assistance, but most were left feeling apprehensive and unsupported. Conceding to this study's results, it seems that, if the interviewed carers were well-informed and could accept their situation rather than react emotionally (COFACE<sup>14</sup>), they might also have more satisfactory family relationships and communicate more effectively. Burke (2003) highlighted the importance of jointly assessing and educating, since carers need to know how to cope in order to effectively help.

Data findings also indicated that the plight of mental health carers was somewhat distinctive: experiences of violence and coercion, or witnessing the dissolution of family dynamics, differed from the experiences of those who cared for people with other somatic conditions such as disability, serious illness or frailty (Broady & Stones, 2015). These differences have important implications when educating, recognising and supporting mental health carers; a staggering 93% of them would appreciate additional support in their caregiving role (EUFAMI-France, 2015). Robinson *et al* (2008) asserted that carers' mental health status and needs could go unidentified by professionals as the latter focused on patients' needs. Carers may avoid identifying their own mental health problems due to the fact that "their ill loved-one cannot afford for them to be sick or unavailable" (three interviewed mother-carers referred to this). As such, the mental health needs of carers may remain unaddressed and may have long-term adverse effects on the well-being of both the "mentally-ill" patient and the family carer. Another part of the data results showed a sibling carer, Vivienne, who took care of her "mentally-ill" brother and her mother, diagnosed with Alzheimer's. This French carer took on different caring roles according to the family member; this may lead to poorer outcomes as she looks after both patients. But according to Sanders (2004) carers may not want to give up caregiving as long as they are supported, that they receive information, that they are recognised as having value, and that their ill relatives are also professionally treated.

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<sup>14</sup> Confédération des organisations familiales de l'Union européenne

#### 4.3.1 Preliminary educational training

After having considered all of the interviews, the results from the collected data and the literature, our research question – “How can carers in France be supported in their caregiving experiences towards a mentally-ill relative?” – can be answered through preliminary educational training. This would allow carers to acquire essential knowledge, feel valued and understand how to cope with the mental health disability of their ill relative. The carers we interviewed had never been prepared or trained to face the stress of caregiving. They had not received guidance at the onset of the "mental illness", nor when the diagnosis had been announced, nor in the context of daily activities, thus causing further disruptions in family dynamics.

Carré (2005 p152) argued that, in the field of training, professionals should pay special attention to two aspects inherent to the act of learning: one's prior representations and reflecting on one's own ways of learning. Thus, with reference to the second objective of this study, health professionals could use the data findings herewith as a base to create educational goals for carers. These goals would enable carers to better understand the "mental illness" of their relative. They could then start to accept the consequences of the illness on their daily lives; they could learn strategies to interact more effectively with their sick family member and they could be coached to preserve themselves while also helping their ill loved-one.

Such an early individual intervention program could be set-up as a one-time orientation session that would coincide with the patient's admission in psychiatry (Scharfstein & Libbey, 1982.) In the hospital, such sessions could be hosted by health professionals with contributions by qualified peer support or peer health mediators<sup>15</sup>. Social networks could also be introduced. An example of an association advocating for the entourage of people living with “mental disorders” is UNAFAM.

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<sup>15</sup> A peer health mediator is a collaborator who has lived with a mental health problem and who shares his/her life and recovery story to give hope, to serve as a role model, to provide inspiration, to support and inform people in similar situations (Repper & Carter, 2010).

#### 4.3.2 Individual educational “diagnosis”

The first stage in a carer’s learning process should be an individual educational “diagnosis” (D’Ivernois & Gagnayre, 2016 p.75). Health professionals would assess different aspects of the carer’s life and interpret their initial representations, subjective burdens and coping needs as caregivers. Likewise, to assess a carer’s potential, their requests and projects should be taken into account in order to offer a personalised educational program. Furthermore, the “diagnosis” would help health professionals identify the types, strategies and methods of education most likely to meet the needs and objectives identified by the families in need (D’Ivernois & Gagnayre, 2016 p.41).

#### 4.3.3 Minimising reactivity, a socio-constructivist approach

From a socio-constructivist perspective, Jonnaert (2002 p.77) stated that skills were defined by situations and that these were forms of knowledge applied to problematic circumstances. A caregiving experience then becomes the central moment of learning for the carer.

For instance, one of the themes of the educational program could focus on “minimizing reactivity” – a coping strategy to accept problematic issues as based on the “Resiliency Model of Family Adjustment and Adaptation” (McCubbin *et al*, 2001). This is a teachable skill and a healthy coping ability as family members gain knowledge in the face of adversity and can stay “level-headed” (Crowe & Lyness 2014). It is important for mental health professionals to consider this socio-constructivist approach as it can allow communication, cohesion and flexibility during challenging situations. Positive relationships among carers and “mentally-ill” patients can be strengthened, particularly in families where disabilities hinder communication.

#### 4.3.4 Home visits, a form of continuing education

Additionally, “home-visits” could be strengthened and the welfare of carers could be taken into account. It could be a “follow-up” activity in one’s continuing education or the assessment of a carer’s previous training; the carers’



sense of empowerment and his/her interactions within the family would be evaluated, as recommended by this study's second objective. The 2017 National strategy<sup>16</sup> has recommended such schemes and the HAS<sup>17</sup> indicated that the global context of medico-social carer support should change. However, these instructions come at a time of structural crisis wherein the system is being reorganised and French public health budgets have been reduced.

The overall purpose of the carer educational course suggested above would not be to professionalise carers nor to replace health professionals. It would instead be used to empower mental health carers and to encourage positive relationships within families. It would also constitute a first step towards creating forms of partnership, inclusion and coordination in a triangular relationship of care between health professionals, "mentally-ill" patients and carers.

In his book *Proximologie*<sup>18</sup> (2006), Joublin stated: "Families are caring, loving *suffering yet faithful with their ailing loved-one.*" But how much longer will these French carers have to wait before being empowered? They are as yet "unarmed" when facing the daily burdens and challenges of their loved one's "mental illness".

#### 4.4 Limitations and perspectives

Some limitations must be considered due to the small size of the sample data. The latter restricts us in representing the entire population of carers in France. We must also consider the challenges we encountered when recruiting participants who were willing to share their caregiving experiences towards a "mentally-ill" person. This is perhaps another downside of the overwhelmingly negative representation of "mental illness" in France. Likewise, future studies would need to be conducted using specific questionnaires intended for spouse-carers and child-carers.

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<sup>16</sup> *Stratégie nationale pour soutenir et accompagner les aidants de personnes en situation de handicap*

<sup>17</sup> *Haute Autorité de Santé*

<sup>18</sup> A research area dedicated to the study of the relationship between patients and their families.

It is imperative to state, however, that some international references in the literature indicated that caring was also composed of positive elements and that it was not universally harmful to the carers' psychological well-being (Williams & Mfoafo-M'Carthy, 2006). In our study, two participants mentioned the experience as enriching and another focused on positive emotions such as love. Caregiving can be a source of achievement (Lemoine *et al*, 2005). As an experience, it is not necessarily unidimensional but can be difficult and rewarding, burdensome and gratifying when carers are empowered and when they receive the training they need.

## 5 Conclusion

When establishing cross-cultural comparisons between developing and developed countries, the data and the literature show that carers have better access to health and economic resources in France, but that most French families can reach breaking points when dealing with the emotional and psychological impacts of caring for a "mentally-ill" relative. The voices of carers ring through this paper as they call for greater support.

This qualitative research study, which explored the caregiving experiences of mental health carers in France, can provide vital data to help professionals and policymakers advocate for better support for mental health carers at local, national and international levels. Carers, would greatly benefit from an early educational program which would promote enlightenment unlike current negative representations of "mental illness" in France. They would gain from learning about psychiatric interventions, they would broaden their social networks and they would be fully included in the treatment plans of their ailing loved ones.

Moreover, empowered French carers – and, by extension, carers all over the world – could overcome their subjective burdens by focusing on developing personal strengths, coping skills and positive communication, all in an effort to prevent relationships from breaking down within families.



Lastly, French carers must promptly receive assistance from the French government and be assured quality support from trained mental health professionals. This would ensure better family dynamics and the successful coordination of the triangular relationship of care between health professionals, patients with mental conditions and their carers.

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## **Structured Abstract:**

### **Purpose**

France, once a pioneer in psychiatry, is now sinking as its population faces major mental health challenges. This includes the 12 Million French individuals with psychiatric conditions, the lack of appropriate structures and the shortage of skilled mental health professionals, but it also leaves families in critical situations. The aim of this qualitative research was to explore the carers' caregiving experiences and to suggest ways to organise educational programs to support mental health carers in France.

### **Method**

Research was conducted from January 2018 to November 2019. It included French carers of patients with mental conditions. Recorded semi-structured interviews were used and findings were analysed through an inductive thematic analysis and regrouped into key themes.

### **Findings**

Participants had overwhelming negative representations of "mental illness". The fact that they were excluded from participating in the patient's health management further added to their misconceptions around mental disability, it limited their communication with their family and amplified their burdens.

### **Research implications**

There is an urgent need for carer empowerment; carers should be included in educational programs; they should benefit from French government subsidies and social-network assistance and receive quality assistance by trained mental health professionals. The critical situation of carers can only be addressed by combining these three steps and through the action of appropriate actors in the field of mental health, thus alleviating the current paradigm of psychiatric care in France.

### **Value**

Thousands of research papers regarding carers have been published in other countries. And yet, to our knowledge, only a few investigations on French mental health carers have been conducted to this day. The singularity of this research lies in the rare individual interviews which provided us with first-hand testimonies of mental health carers in France. This data could be of vital aid for professionals and for policymakers when advocating for better support of carers in mental health.

**Keywords:** French carers, Mental health, Caregiving experiences, Education.

**Article Classification:** Research Paper

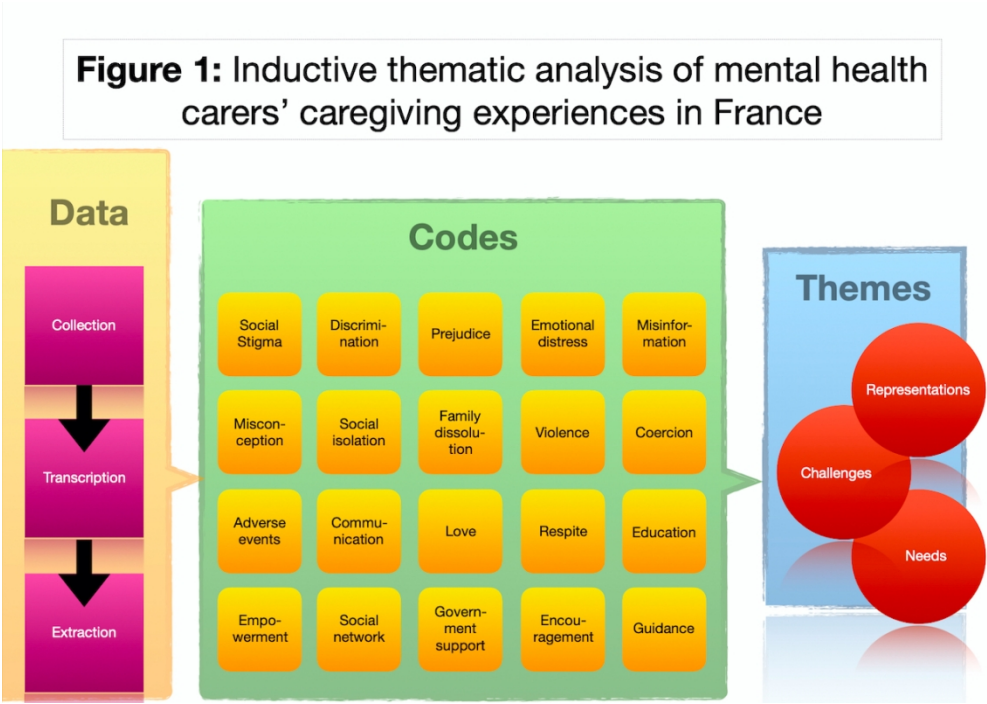


Figure 1: Inductive thematic analysis of mental health carers caregiving experiences in France

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