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# The Lived Experiences of Family Members and Carers of People with Psychosis: A Bottom-Up Review Co-Written by Experts by Experience and Academics

Andrés Estradé<sup>a</sup> Juliana Onwumere<sup>b, c, d</sup> Jemma Venables<sup>a</sup> Lorenzo Gilardi<sup>e</sup>  
Ana Cabrera<sup>f</sup> Joseba Rico<sup>f</sup> Arif Hoque<sup>g</sup> Jummy Otaiku<sup>g</sup> Nicholas Hunter<sup>h</sup>  
Péter Kéri<sup>i</sup> Lily Kpodo<sup>j</sup> Charlene Sunkel<sup>k</sup> Jianan Bao<sup>l, m</sup> David Shiers<sup>n, o, p</sup>  
Ilaria Bonoldi<sup>q</sup> Elizabeth Kuipers<sup>b, c, d</sup> Paolo Fusar-Poli<sup>a, b, m, r</sup>

<sup>a</sup>Early Psychosis: Interventions and Clinical-detection (EPIC) Lab, Department of Psychosis Studies, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK; <sup>b</sup>National Institute for Health and Care Research, Maudsley Biomedical Research Centre, London, UK; <sup>c</sup>Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK; <sup>d</sup>Bethlem Royal Hospital, South London and Maudsley NHS Foundation Trust, Beckenham, UK; <sup>e</sup>Independent scholar, Como, Italy; <sup>f</sup>Asociación Madrileña de Amigos y Familiares de Personas con Esquizofrenia (AMAFE), Madrid, Spain; <sup>g</sup>Young Person's Mental Health Advisory Group (YPMHAG), King's College London, London, UK; <sup>h</sup>National Health System (NHS) South London and Maudsley (SLaM) Recovery College, London, UK; <sup>i</sup>Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe), Brussels, Belgium; <sup>j</sup>South London and Maudsley (SLaM) NHS Foundation Trust, London, UK; <sup>k</sup>Global Mental Health Peer Network (GMHPN), Johannesburg, South Africa; <sup>l</sup>Department of Forensic and Neurodevelopment Sciences, King's College London, London, UK; <sup>m</sup>OASIS Service, South London and Maudsley NHS Foundation Trust, London, UK; <sup>n</sup>Psychosis Research Unit, Greater Manchester Mental Health NHS Trust, Manchester, UK; <sup>o</sup>Division of Psychology and Mental Health, University of Manchester, Manchester, UK; <sup>p</sup>School of Medicine, Keele University, Staffordshire, Newcastle, UK; <sup>q</sup>Department of Psychosis Studies, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK; <sup>r</sup>Department of Brain and Behavioral Sciences, University of Pavia, Pavia, Italy

## Keywords

Psychosis · Schizophrenia · Lived experiences · Family · Carers

## Abstract

Informal caregivers of individuals affected by psychotic disorder can play a key role in the recovery process. However, little research has been conducted on the lived experiences of carers and family members. We conducted a bottom-up (from lived experience to theory) review of first-person accounts, co-written between academics and experts by experience, to identify key experiential themes. First-person accounts of carers, relatives, and individuals with psychosis were screened and discussed in collaborative workshops involving individuals with lived experiences of psychosis, family members, and carers, representing various organizations. The lived experiences of family members and carers were characterized by experiential themes related to dealing with the unexpected news, the search for a reason behind the

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## Additional information

Andrés Estradé and Juliana Onwumere are joint first authors.

disorder, living with difficult and negative emotions, dealing with loss, feeling lost in fragmented healthcare systems, feeling invisible and wanting to be active partners in care, struggling to communicate with the affected person, fighting stigma and isolation, dealing with an uncertain future, and learning from one's mistakes and building resilience and hope. Our findings bring forth the voices of relatives and informal carers of people with psychosis, by highlighting some of the common themes of their lived experiences from the time of the initial diagnosis and throughout the different clinical stages of the disorder. Informal carers are key stakeholders who can play a strategic role, and their contributions in the recovery process merit recognition and active support by mental health professionals.

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## Introduction

Psychotic disorders have an estimated prevalence of 9.57 per 1,000 [1], with schizophrenia affecting over 20 million people around the world [2]. Psychosis usually begins during teenage years and early adulthood [3], a critical developmental period for the achievement of occupational and relationship goals [4, 5]. Psychotic disorders are associated with high economic costs and can severely disrupt the life of affected individuals [6], in addition to high levels of family burden [7–12] as relatives often assume the role of informal carers to provide ongoing support to the affected person.

Informal carers of people with mental health difficulties, including psychotic disorders, can be anyone but will often be close relatives such as parents, partners, siblings, and young or adult children. Their role in supporting recovery experiences for individuals with psychosis is substantial and widely recognized by different groups, including service users themselves, health and social care providers, governments, and policy makers. These contributions assume even greater value when health and social care provisions undergo changes such as transitioning from a focus on institutional to community care provision or through natural disasters including global pandemics [13]. In recognition of their value and needs, recommendations to provide carer- and family-based interventions feature in several best practice and treatment guidelines for psychosis, including the UK [14], the USA [15], Canada [16], and Australia [17]. Alongside their contributions to optimizing service user outcomes, which can include reducing the need for and length of psychiatric hospital admissions [18] and improving life expectan-

cy [19], the literature also speaks to a broad range of other experiences that carers can encounter in context of their caregiving role. However, studies on the lived experiences of relatives lag behind research on individuals affected with psychosis [20].

## Methods

In this study, we explore the lived experiences of family members and carers of people with psychosis through a bottom-up review (i.e., from lived experience to theory) of first-person accounts, co-written between academics and experts by experience. We replicate the method of our previous publication on the lived experiences of psychosis [6]. Firstly, a collaborative team of academics and individuals with lived experiences of psychosis was established. This core writing group screened all first-person accounts published in *Schizophrenia Bulletin* between 1980 and 2021 [21] to identify first-person accounts of family members or carers of individuals with psychosis. We selected *Schizophrenia Bulletin*'s "First Person Account" series as the primary source of narratives due representing the longest-running set of first-person accounts published in an academic journal, going back to 1979. The series is not limited to individuals with a diagnosis of psychosis, also including accounts by relatives, carers, and friends of individuals affected by the disorder. Throughout the years, the series has maintained a consistent format that facilitates cross-comparison across different accounts. In addition, following an initial selection and consensus by the journal's editor and managing editor, the first-person accounts do not usually go through a formal revision process, allowing for authentic narratives of the lived experiences of authors and for authors to also present as anonymous [22]. Nonetheless, recognizing that only a subset of carer accounts are published in the journal, we augmented our overview with additional publications from groups that are typically underrepresented in the literature and spoke to carer experiences across the illness course (e.g., during the prodromal phase) and varied demography (e.g., racially minoritized groups). Additional sources were selected following non-systematized searches in online databases and published books, informed by stakeholders with lived experiences. Selected sources included primary accounts of relatives, friends, or informal carers of individuals with psychosis. Complementary first-person accounts by individuals with psychosis were also included if they addressed the individual's relationships with their family members or caregivers.

In a second step, two researchers from the core writing group (AE and JO) independently conducted a thematic analysis of the material through a process of (1) exploratory re-reading of sources; (2) generation of initial codes; (3) grouping of codes into experiential statements; (4) identification and naming of common experiential themes across sources [23]. An inductive ("bottom-up") [24] and iterative approach was chosen at this stage to allow for themes to emerge from the raw data. This process resulted in a tentative list of common experiential themes across sources.

Thirdly, themes were shared and discussed in two collaborative workshops (20th and 22nd October 2021) involving numerous individuals with lived experiences of psychosis, in addition to family members and carers. Workshops were conducted as part of our

“lived experiences of psychosis” project, which was not limited to the experience of carers and family members [6]. Workshops involved representatives from the following organizations: Global Mental Health Peer Network (<https://www.gmhpn.org>); the Global Alliance of Mental Illness Advocacy Networks (GAMIAN) – Europe (<https://www.gamian.eu>); the South London and Maudsley NHS Foundation Trust (<https://www.slam.nhs.uk>); the Young Person’s Mental Health Advisory Group (<https://www.kcl.ac.uk/research/ypmhag>); the Outreach And Support in South-London (OASIS) (<https://www.meandmymind.nhs.uk>) Service Users Group; the South London and Maudsley NHS Recovery College (<https://www.slamrecoverycollege.co.uk>); the Black and Minority Ethnic Health Forum Croydon (<https://cbmeforum.org>); the UK Mental Health Foundation (<https://www.mentalhealth.org.uk>); the Faces and Voices of Recovery (<https://facesandvoicesofrecovery.org>); and the Asociación Madrileña de Amigos y Familiares de Personas con Esquizofrenia (AMAFE) (<https://www.amafe.org>). Representatives from service user and family groups were reimbursed for their time allocated to the project in accordance with the guidelines by the UK National Institute for Health Research (<https://www.invo.org.uk>). Overall, 18 individuals with different types of lived experiences (8 female, 10 male) participated in collaborative workshops, in the process of manuscript review and editing or both. Participants included individuals with lived experiences of psychosis ( $n = 12$ ) and individuals occupying professional or executive positions in organizations advocating for the rights of service users and family members ( $n = 6$ ).

As a final step, the selection of experiential themes was revised and adjusted after integrating feedback from workshop participants. The revised draft of experiential themes was again shared among collaborators and finalized iteratively. All individuals with lived experiences of psychosis, family members, and carers involved in the project were invited to be co-authors. Our final selection of sources included 38 first-person accounts from *Schizophrenia Bulletin* [25–61] and 10 other sources including autobiographical books, qualitative research reports, and book compilations [9, 62–72]. Overall, the sample from included sources is comprised of 192 participants ( $n = 133$  female,  $n = 54$  male,  $n = 5$  gender non-specified). Of these,  $n = 159$  (82.8%) are carers or family members,  $n = 32$  (16.7%) are individuals with lived experience of psychosis, and one individual occupied both a service-user and family member role [28]. Among 160 individuals occupying a carer/family role, 68.1% are parents, 10% partner/spouse, 6.9% siblings, 3.8% sons/daughters, 2.5% grandparents, and the rest (9.4%) occupy either another family role or did not specify the familial relationship with the affected individual. One individual occupied both the roles of daughter and mother of individuals with psychosis [38].

## Results

In the following section, we present ten key experiential themes emerging from the process previously described. These experiential themes relate to the interaction of the affected person with their family environment, which includes close relatives such as parents, partners, siblings, and young or adult children, as well as other car-

ers. The words spoken by participants of our collaborative workshops, or written in the first-person accounts, are presented verbatim in italics. Finally, our findings are discussed with reference to the broader literature on caregiving experiences and implications for service provision.

### *Dealing with the Unexpected and Shocking News*

*“I do not understand what happened, what went wrong, when it started to go wrong. Somewhere in his late teens? ‘Classic,’ the psychiatrists said. Classic? What did we know of schizophrenia, classic or not? We barely knew the word”* [26]. When families are first confronted with psychosis and its diagnosis, they commonly describe an experience of feeling shocked and utterly unprepared for understanding the condition and its associated needs [26, 37, 48]: *“Nothing in her growing-up years could have prepared us for the shock and devastation of seeing this normal, happy child become totally incapacitated by schizophrenia”* [48]. This emerged as a profound lack of mental health literacy: *“What we knew about schizophrenia, in the beginning, we could have written on the head of a pin”* [48]. Unknowing the condition, relatives interpreted early behavioural changes in the context of the normal fluctuations of emotions of adolescence or young adulthood: *“I don’t know whether ‘belittled’ is the right word, but I don’t think I took her fears seriously. I used to think that she was being dramatic”* [62]. The early signs of the emerging disorder often go unnoticed during the prodromal phase as affected individuals manage to keep them hidden from their relatives and friends (see above). When confronted with these early signs and associated behavioural changes during the prodrome, family members feel puzzled and stunned, not knowing how to respond [56–59], or thinking of any possible explanation other than a mental disorder: *“When someone you know and love begins to slowly change before your eyes, no one thinks, ‘Hmmm, he must be mentally ill.’ You think[...] of any excuse but mental illness”* [65].

In the face of this shock and unpreparedness, families and carers developed variable coping strategies. Some family members attempted to minimize the impact of the disorder: *“I think within families there can be a tendency towards wishful thinking – they desperately want the family member to be better and can’t quite foresee (because who could ever imagine it?) just how bad the illness can become without treatment”* (personal communication during the workshop). Other families tried to quickly learn as much as they could about the disorder to develop a sense of control [26, 65].

### Searching for an Obscure and Hidden Reason

"My parents thought that what happened was because of them. We discussed traumatic events occurring earlier in my life, which did not help because my parents started blaming themselves after that" (personal communication during the workshop). After receiving a diagnosis of psychotic disorder, families can begin a process of retrospectively searching for single causal events and, in doing so, identify a plausible explanation. "Why us?" or "what did we do wrong?" were recurring questions during the early stages of the disorder [60, 66]. Unfortunately, the process often results in feelings of guilt and self-blame [27, 37, 60, 61, 67]. On the one hand, carers and close family members experience guilt for not recognizing early warning signs of the disorder: "[...] my mother commented to me, after I had visited my parents for a week, 'I feel like I should have done something for you when you were home, but you seemed so normal'" [28]. Family members also blamed themselves and felt responsible for their behaviours: "I blamed myself. It had to be someone's fault. Maybe I shouldn't have smoked when I was pregnant. Maybe I never should have married my ex-husband because he was an alcoholic and verbally abusive. Maybe I shouldn't have been watching my weight so closely when I was pregnant" [37]. On the other hand, family members may accuse and blame each other: "You feel responsible for everything that happens in your son's life. So you have all the weight on your shoulders. [...] When he tried to kill himself, my husband blamed me. 'Where were you?' he said. I said, 'What do you mean, where were you? Where were you?'" [9].

### Living with Difficult and Negative Emotions

"Yes, he was and is an expert manipulator. He infuriates me one minute, and the next minute he just breaks my heart. How do I escape this maze I am in?" [60]. Family members and carers highlighted how the manifestation of the disorder led to anger and inner conflicts. Frustration or resentment emerged from the economic [27, 65], personal, and social [29, 59, 65] sacrifices that families made to care for their loved ones [26]: "He disrupted my childhood, he disrupted my time with my parents, he disrupted my life, and I wanted it to end [...] I would often direct my ignorance into anger at Fred for being ill [...] I wanted to believe that Fred could control this [...]" [65]. Also, young family members often may feel "neglected" [29, 30] as the attention is focused towards the ill member of the family: "My own concerns were often dwarfed by Andy's larger problems, while my joys and successes seemed even more trivial" [30]. Other family members directed their anger towards the disease itself: "I hate schizophre-

nia. I hate it! Schizophrenia robs its victims of everything important in life. It's ugly, selfish, and takes away simple joys in life such as laughing, holding down a job, and being able to have a conversation with anyone" [37]. These processes can be complicated by the difficulty of separating the disorder from the affected person: "How can I hate the disease without hating my sister along with it when the two are almost inseparable?" [31].

This mixture of negative emotions clashed with the love carers and families felt towards the affected person and their sense of responsibility and caring, creating an inner conflict or tension [30, 60]: "I felt guilty because I began to resent the endless struggle of dealing with Jon's strange world and the endless daily complications it brought about" [25]. Over time, the intense anger of the early days often recede as families develop a better understanding for the disorder and their relative [60, 65], as well as improved self-compassion, to reduce their sense of guilt: "Eventually I came to realize the damage my constant anger was doing to me [...] we took deep breaths and recalled [...] that parents cannot cause schizophrenia" [26].

### Dealing with the Loss of a Relationship and Navigating the Start of a New One

Family members and carers feel that the disorder robbed them of their loved one as they had known them, who now present as a "stranger" [67, 68], changed in their personality as well as physical appearance [31–34]: "I just felt that her personality completely disintegrated and I don't know, it was such a huge level of stress" [69]. In addition, families feel that the disorder disrupts or takes away their plans [48] and the memories [30] they shared with their loved ones. This leads to a complex bereavement process and eventually of having to learn to accept and love a new family member: "The woman who was once attractive, confident, kind, discerning, and popular became a social recluse, a sullen figure, and a 'mumbler' of paranoid notions" [35]. This process of adjusting to the new affected familial member is extremely painful [34] and requires dealing with enduring feelings of loss and grief [29, 36] about previous images and relationships with relatives: "As for my relationship as an adult with my mother, I would be lying to say that I do not think about her condition daily. I also grieve over the loss of my mother as I knew her before the first episode" [32]. The cycle of grief and loss is often enduring [30, 48], as well as fluctuating, depending on the clinical course of the disorder: "In the past year, a new Cindy has emerged. Where once there was a rather unfriendly, often unpleasant girl, there is now an amiable, more responsive person" [48].

The process of mourning for a loved one with psychosis is particularly complicated for families and carers that co-reside or remain in close contact, struggling with the daily alive impact of the disorder: *“Although grieving for someone who has died is painful, some sense of peace and acceptance is ultimately possible. However, mourning for a loved one who is alive – in your very presence and yet in vital ways inaccessible to you – has a lonely, unreal quality that is extraordinarily painful”* [30]. Mourning can be complicated by the difficulties in separating the disorder from the affected relative’s personality or self, as noted above: *“Sometimes it is impossible to tell where the disease ends, and my sister begins. When a disease infects the mind, the person and the disease become almost one”* [31]. As a result, families and carers can feel as if they are constantly in the search for the “real” person behind the symptoms: *“I treasure the times Cindy looks at me and tells me I’m beautiful when she tells me my dress is pretty [...]. This is the ‘real’ Cindy speaking – my sweet, generous, funny, intelligent daughter”* [48].

#### *Feeling Lost in Fragmented Healthcare Pathways*

*“After the initial shock, families look for treatment”* (personal communication during the workshop). Families and carers highlighted the stressful experience of trying to elicit an adequate and timely response from the healthcare system: *“The hospital couldn’t hold Burt unless he was a danger to himself or someone else. I was devastated and exhausted. I was hitting a dead end [...] ‘What does a person have to do around here to get some help?’”* [37]. Carers and family members described a deep sense of frustration in trying to access the required help, which was too often lived as delayed, complicated, burdensome, and an unfair process [37, 38]. Frequently, families felt that the healthcare system responded only when a crisis emerged [27, 37]: *“[I’m] just frustrated and worn out with it all. Just, I can’t say I blame an individual; I think it’s the system as a whole. [...] I really don’t think you should have to hit rock bottom before somebody does something”* [62]. When a response emerged, it was at times experienced as insufficient [30] and not personalized to the practical needs of the family [33, 67, 70]. Other familiar sources of frustration for families included receiving contradictory messages from fragmented services [26, 65], the lack of continuity in care [39, 67, 71], and support following hospital discharge [35]: *“My experience with the mental health services has been that there is no awareness of the need for continuity – the staff in our centre seem to change almost monthly”* [67]. Mental health advocacy was a coping strategy that some families found to channel their anger

and frustration towards pursuing better treatments and regaining a sense of agency in the healthcare system [33, 40, 66].

#### *Feeling Invisible and Wanting to Be Active Partners in Care*

*“What many don’t understand about schizophrenia is that it is an illness that affects the entire family, yet it’s rarely treated as a family”* [65]. Family members often assume the new role of “carers,” for which they are rarely given a choice about and often feel unprepared for: *“I was his sister; confused, uncertain, concerned, but not inclined to reach in and take over any of my brother’s autonomy. Now I was to become his primary caregiver/mother, a role I felt I had no choice but to assume”* [59]. In addition, families and carers often feel excluded from their loved one’s treatment [26, 68, 70, 72]: *“I felt that I was invisible, as nobody seemed to notice me”*[72], potentially leading to the mishandling in the care plan itself: *“I was not asked about my views on my son’s history, and therefore several things were recorded as delusions that were, in fact, true”* [70]. At times, they also felt a lack of sympathy from the healthcare team [26]. As a result of these problems, many families resort to a trial-and-error approach [25] to managing situations while feeling willing to do anything in their power [34, 37, 41–43]. This sense of insecurity can lead to persisting doubts about whether they are doing the right thing for their loved one [70], to the feeling that they could or should have done more [65], to arguments about what is the right thing to do [44], and to a persistent sense of powerlessness or helplessness [37, 48, 66]. As a result, families and carers frequently wish to be more involved in the care plan and receive more guidance and mental health literacy: *“I am convinced that if someone had helped me understand my husband’s illness without my having to go through the long, painful process of learning step by step, and if I had been made aware of my own weaknesses before being drawn into inescapable vicious circles, much pain could have been avoided”*[25]. On some occasions, families feel they were directly or indirectly stigmatized by the healthcare team, adding to their feelings of self-blame [68, 70]: *“My girl had become a stranger to me, and I was a stranger to her. I was no longer her loved and trusted mother, but often seen as ‘the enemy’ (a view sometimes clearly shared by ward staff)”* [68].

### *Struggling to Communicate with the Affected Individual*

A frequent experience of family members and carers is inability to communicate with their loved ones as desired. On the one hand, they often feel the affected person had become inaccessible to them, finding it difficult to establish a meaningful communication [48] or to understand their inner struggles [25]: “*What must [he] be going through? I ask him if he is happy, and he says he is. But what is happiness to him now?*” [37]. As noted above, the communication problems may arouse intense feelings of guilt [66]: “*I felt guilty because I could neither ease his suffering nor give him the confidence he lacked so dramatically*” [25]. On the other hand, carers and family members often feel afraid of the unpredictable – at times aggressive [25, 27, 35, 38, 42, 59, 67] – responses of the person [26, 38, 68]. A member of our collaborative team commented: “*One big theme is families not knowing how to communicate with the person. In my case, at times, they decided not to communicate due to fear of how I might respond*” (personal communication during the workshop). Another recurrent communication challenge for families is “*treatment persuasion*” (personal communication during the workshop), i.e., securing the relative’s agreement to engage in assessment and treatments [38, 43, 45, 46]. Although relatives try to reason, negotiate, or beg [36, 38, 43, 46] with their loved ones to engage with treatment, this results in an exhausting and frustrating process for which they feel poorly equipped.

### *Fighting Stigma and Isolation*

Isolation is an essential component of the lived experience of families and carers: “*Our social life was the first thing that changed noticeably. When we were with friends or relatives, my husband started making embarrassing remarks when he thought he heard them conspiring against him [...] Gradually, most of our friends drifted away*” [25]. Stigma, misunderstanding, and myths about mental health problems significantly contribute to the sense of isolation and prompt family members to keep their relative’s disorder hidden from other people [27, 29, 47, 70]: “*And so we were thrust into the stigma/blame loop. ‘She’s the one with the crazy son. Maybe he’s crazy because she is?’*” Families and carers also fear being misunderstood: “*No, I didn’t tell the church, I kept it secret from the church members, I didn’t tell them. I don’t think they would have understood*” [63]. Consequently, families experience a disruption of critical social networks for their relatives and themselves, including family bonds breaking apart or becoming weaker [26, 27, 38, 70] and the gradual loss of friendship [26, 29, 48, 65].

Carers and families can also feel they do not have people to rely on to find advice [26, 68] and bear the impact of caregiving privately: “*In this new situation of a mental health problem, I had neither love nor support, and did not know where to find help. There was no one with whom I could share this burden. The whole territory of mental health problems was strange, unpredictable and frightening*” [68]. Carers and family members reported experiencing persistent psychological pain [42] that was not immediately or always visible to others, rarely enquired about, and forced them to wear a daily fake persona: “*I remain stoic, to keep unspeakable things to myself, alone [...] I continue to put on my ‘public’ face as I go about my day*” [49]. As for the affected individuals, psychosis can cause family members and carers to feel split between the two worlds: the “*normal*” social world and their “*surreal*” private world of mental disorders [49, 68]. Some carers, however, report finally being able to find the needed understanding and support once they contact other carers [26] experiencing the same difficulties: “*When I meet them, we don’t need to explain ourselves*” [49]. With the help of the carers, family members can also learn to be less affected by the comments of others: “*You cannot take it personally, even though it may be difficult not to. People that do not understand mental illness can’t possibly even begin to comprehend what your life is like*” [65].

### *Dealing with Uncertainties Regarding the Future*

“*The hardest part of the illness is the fact that it is so unpredictable*” [65]. Families are faced with the reality of an uncertain future for themselves and their loved ones. The unpredictable and, for many, the relapsing-remitting course of the disorder lead carers to feel discouraged each time the symptoms emerge again after a period of remission: “*Sometimes, following meetings where his conversation seemed completely ‘normal,’ I would find myself feeling hopeful for his full recovery. But the psychosis would always resurface, seemingly worse every time*” [36]. At times, the unpredictability leads to a sense of entrapment [29, 64]. Also, unpredictability leads carers to be in a state of permanent anxiety [25] or vigilance, in expectancy of the following “*bad news*” [34, 42, 46], including the ever-present risk of self-harm or suicide [35, 46, 64, 67]. As such, family members have to learn that uncertainty about the future is an integral part of their experience of psychosis [25, 65].

Younger family members recall feeling intense fear for the uncertainty that the same would happen to them at some time in the future [29, 30]: “*Feelings of shame and fear overwhelmed me in those early years, shame that my*

friends would find out that my mother was ‘different’ and fear that I would be ‘different’ too” [29]. After they grow older and the fear for themselves passes, the sense of uncertainty is transferred to their children: “When I married and had children, I tried to compensate with good parenting skills for any predisposition toward mental illness they might have inherited from their grandfather” [46].

#### *Learning from One’s Mistakes and Building Resilience and Hope*

With time, some families report being able to become more resilient, accepting, and understanding the affected person, even if their sense of loss or disappointment is not completely gone [29, 60]: “[I learnt] accepting my handicapped son. I encourage him to make himself useful by working but do not demand or expect him to achieve. [...] I do not require perfection” [60]. Families can also develop a better understanding of their limitations: “It’s so important to find some kind of support, or you will be eaten alive by the same illness that your loved one suffers from” [65]. Maintaining a sense of hope was highlighted by families as a key ingredient to keep moving forward [26, 37, 60, 65]. Carers report learning over time to adapt and adjust their expectations to adopt a realistic sense of hope: “People tell me there is always hope, but I ask them how you can have hope when things have just gotten worse for years. I would rather accept the present than have false hope. I can have some peace with that” [37].

In addition, some family members can find a sense of meaning in the experience of the disorder itself: “[...] feel as though Fred was put on this earth for a reason, and we think that reason is so that we can share his story with other families” [65]. Some families accept the disorder through a newfound sense of perspective: “Overcoming everyday hurdles has more significance for us now than in the past. We no longer take things for granted. And rather than speculate on the future, we accept only what each day brings” [42]. The experience of psychosis can also provide a sense of purpose. As the daughter of a mother with psychosis recalls: “I decided to devote my life to helping difficult children. I have been successful in my work, which includes forming relationships with the mothers of my students, [especially the ones with schizophrenia] whom I visit on the wards during their periods of hospitalization” [29]. Finally, a strengthened sense of love, appreciation [36], and support for the relative after all their struggles can also emerge: “The girl with the clogs is the same girl who cooked us dinner; she is the same girl who fought her way through college. That is who my sister is, and that is why I can love her now more than ever” [31].

While families vary in the level of support they can provide, they are frequently considered by individuals with psychosis as essential sources of hope and support throughout all phases of the disorder [50–54]: “My immediate family is the greatest asset I have and the most important aspect of my life. They know who I am and accept me every bit. They have supported me throughout the illness, and they are supporting me as I get back on my feet to lead a ‘normal life’” [55].

## **Discussion**

This paper sought to extend our understanding of the lived experience of family and carers of people with a diagnosis of psychosis. We approached the review acknowledging that our first-hand accounts could not be representative of all carers in terms of their lived experience, socio-demography (including age and racial and ethnic backgrounds), intersectionality, country of origin, and the healthcare systems and infrastructure they utilize. In addition, we conducted a non-systematic selection of complementary sources, as well as opting for a convenience sampling of collaborators that included individuals with lived experiences of psychosis and carers/family members, as part of our larger project that was not limited to the experience of carers and relatives [6]. Thus, we acknowledge the limitations of the data and methodology and encourage caution in generalizing results to all carer groups.

Nevertheless, our results highlighted how carers reported having a range of emotionally impacting experiences as part of their caregiving role, including their initial reactions of shock, despair, and devastation, alongside reports of fear, self-blame, and persistent worry. There was a sense of living through a major life changing event yet not being afforded time or space to take stock and make sense of their experiences. Carers were often unprepared for the task that lay ahead, which was consistent with the broader literature, confirming that the caregiving role often occurs without preparation time. It is not uncommon for carers to find themselves in a support role without being aware they are in one [73]. Similarly, reports of isolation and its close links to stigma and emotional distress were also key themes. Carers’ awareness and witnessing of illness-related stigma towards their relative, coupled with their own exposure to courtesy stigma (stigma by association), can underpin mechanisms that maintain their isolation and social exclusion [74, 75]. The strong links between carer isolation and lack of support



in carers and poorer mental health outcomes are firmly established [76, 77].

Overall, our findings are consistent with studies of caregiver experiences across the illness course [9, 12, 78–82]. They speak to the different responses and reactions that carers can report in their role [83]. Carers described being adversely affected by the illness, including during the prodromal phase when the situation is less clear, familiar, and permanent. The onset of psychosis, which for many will also include a relapsing remitting course, rarely restricts its effects and negative impacts to the service user. The impact on the wider family network and relationships are acknowledged [84, 85] and reinforce the rationale for providing supportive family interventions [14]. However, the carer accounts illustrated how pathways to securing relevant help and support for their relative and for themselves were often opaque, complicated, and typically effortful and emotionally demanding. This would all occur at a time when carers were already feeling emotionally and physically stretched and forced to navigate unfamiliar health systems, terminology, and an illness that remains linked to high levels of stigma. For many carers, illness-specific related issues (e.g., service user aggression towards carer, suicide attempts, loss of social networks) were key challenges they faced but often in the absence of clear and dedicated service responses. While we know these behaviours are not uncommon and are faced by different carers to varying degrees [81], how we best support families is less clear [86, 87].

A need for understanding the reason behind the illness was a notable feature across carer accounts, particularly during the initial phases. The experience of being in the dark and not knowing why their relative's life and their own had been turned inside out was distressing and frustrating. The knowledge lacuna provided fertile ground for appraisals of self-blame or blame of others, including their relative for the onset of the illness. We know that carer blame attributions are associated with psychological distress and poorer adjustment and coping [88]. On the other hand, service user blame is linked to negative exchanges and interaction styles between carers and service users [73] and underscores the importance of ensuring that carers have access to evidence-based psychoeducation to support a more informed understanding.

Difficulties in communicating positively, clearly, and effectively with their relative, particularly in the context of heightened emotions and ongoing symptoms were emphasized. Communication difficulties in psychotic disorders and between carers and service users have been well documented [89], and strategies to reduce their occur-

rence and/or their negative impacts form a key part of recommended family treatments [73].

The importance of carers' underlining and enduring love and concern for their relative's well-being was evident. This could coexist in parallel with negatively charged emotions towards their relative that were largely linked to behaviours that challenge and to carer perceptions regarding the relative's lack of engagement and commitment to making a recovery and improving their situation and that of the wider family. In addition to taking an active role in encouraging relatives to engage in prescribed treatments and services on offer, carers would also try to discourage behaviours and decisions that would negatively impact their engagement. Acknowledging the multidimensional nature of caregiving experiences also means understanding and accepting how the caregiving role can be associated with both negative and positive experiences, as our carer accounts confirmed. The duality in experiences are in accordance with existing literature [90] as are a greater focus and appreciation of a broader range of carer experiences, not just negative ones.

Reports of loss and grief served as a key theme and have remained a common feature of carer lived experiences in the wider literature [9, 91]. The cyclical nature of carers' reports of loss and grief reflect the notion of grief being an ongoing (or recycled) process [92]. Although accounts captured, to varying degrees, the different layers and components; loss and grief over what once was, with regard to their relative and their health, the relationship they had previously shared, and their way of life were emphasized. We know that loss and the inevitable mourning process can drive different carer presentations and service user focused behaviours over time, including reports of criticism and over involvement [83, 93]. However, our understanding of evidence-based approaches on how best to specifically support carers in psychosis through their ambiguous loss and grief remains in its infancy, relative to their other presenting needs [92, 94] and commonly involves facilitated access to peers via support groups [83].

The narratives from racially minoritized carers might be better understood in the context of the wider literature, confirming significantly elevated levels of psychotic disorders in racially minoritized communities compared to majority groups [95, 96]. Moreover, service users from racially minoritized groups experience more adverse care pathways (e.g., via the criminal justice system), negative care and service experiences, and poorer clinical and social outcomes [97, 98]. Against the backdrop of economic and social migration, we also know that caregiving can

present with additional challenges for those who might also be immigrants and thus navigating parallel transitions and potential socio-economic issues [99].

Carers accounts captured their experiences of isolation and felt a sense of being excluded and marginalized, specifically from the care process and the systems and mechanisms purporting to improve things for their relative. Being recognized for their unique and valuable expertise and contributions they have made, do make, and will often continue to make to their relative's recovery and well-being long after the involvement of service or healthcare professional has ceased was a challenge. We know there can be marked variability in the quality and quantity of carer involvement in services [100]. This theme reflects the long-standing struggles service providers face in ensuring and implementing optimal and acceptable approaches to recognizing, working in partnership, and valuing the experience and expertise of family carers [100–103].

Our current pattern of results is in line with cognitive models of caregiving responses in psychosis, which acknowledge the broad range of caregiving impacts, including positive aspects, the independence of carers' appraisals about their relative's illness and their relative's behaviour, and the importance of providing service level interventions to support carers in their role [83]. The reported neglect of carers' roles would seem somewhat counter-intuitive and at odds with promoting recovery orientated services. In recognition of these gaps, we have previously argued for carer-specific services [104]. Moreover, there are some service examples of carer-focused initiatives that have offered encouraging, albeit, preliminary, findings [105].

Regarding clinical implications, it was evident from the accounts, irrespective of the heterogeneity in reported experiences, illness course, and carer demography, that carers would benefit from unhindered and facilitated access to evidence-based and targeted support from family and carer-based interventions. The interventions can support carer well-being [106], reduce levels of relapse [107], and can be implemented across different settings, including those with low resources [108]. The interventions and delivery approach should also be flexible enough to respond to a change in reported needs and role changes over time particularly as carers advance in their years and their own health needs change [109, 110]. Active enquiry into the lived experiences and impacts of caregiving in psychosis and signposting should be a minimum expectation of all healthcare professionals. Our implications are consistent with the recent updates to the World

Health Organization 2030 mental health action plan that includes a focus on increasing the involvement and empowerment of family carers and provides psychosocial interventions to address their information, support, crisis management, and well-being needs [111].

It would seem remiss, however, to ignore that we exist in a growing climate of ever decreasing resources and where presenting clinical need [112] and the existence of recommended treatments, guidelines [14], and strategic action plans [111] are not always the influencing factors guiding access to services and receipt of care [113]. It is essential, therefore, that the needs of families and carers are recognized, prioritized, and addressed and we move beyond the rhetoric of doing so.

## Conclusion

Recovery from psychosis has been defined in several different ways yet continues to be recognized by many as journey, which, in addition to the service user, the carer is a key stakeholder and can play a strategic role. Understanding the lived experience of psychosis and recovery in service users demands an equal understanding of the lived experiences of carers and their needs. The literature is scarce on service users' lived experience narratives of being cared for by carers [114]. However, it would seem helpful as part of future initiatives to triangulate carer first-hand accounts with service user lived experience accounts of having psychosis and of being cared for to build a more comprehensive and nuanced understanding of the caregiving environment.

## Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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## Author Contributions

Andrés Estradé, Juliana Onwumere, and Jemma Venables participated in study design and manuscript draft and revision and participated in the collaborative workshops. Lorenzo Gilardi, Arif Hoque, Jummy Otaiku, Nicholas Hunter, Péter Kéri, Lily Kpodo, and Charlene Sunkel participated in the collaborative workshops

and manuscript revision process. Ana Cabrera, Joseba Rico, Jianan Bao, and Ilaria Bonoldi participated in the manuscript revision process. David Shiers and Elizabeth Kuipers provided expert revision of the manuscript.

Paolo Fusar-Poli participated in study design and manuscript draft, participated in collaborative workshops, and provided ongoing senior supervision of the project.

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