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ORIGINAL PAPER

The Needs and Experiences of Parents with Psychosis: A Qualitative Interview Study

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Abstract

Over a third of individuals diagnosed with a psychotic disorder are also a parent. The symptoms of psychosis and side effects of antipsychotic medication can impact on parents' awareness of the needs of their children and, at times, the parent may be emotionally and practically unavailable to their child. This study assessed the expressed emotion of parents with psychosis and used qualitative methods to investigate their needs and experience in order to identify how best to support this parent group. Twelve parents with a diagnosed psychotic disorder and with a child aged between 3 and 11 years took part in semi-structured interviews. The majority of parents displayed high levels of warmth and low levels of negativity towards their child. Four themes were generated using reflexive thematic analysis: (1) the impact of psychosis on parenting, (2) the need to protect their child, (3) the need to feel normal, and (4) the impact of parenting stress on psychosis. These results showed how parents want to protect their children and feel normal despite experiencing psychosis. They also highlighted the cyclical relationship between parenting stress and psychotic symptoms, whereby psychotic symptoms can impact on a parent's capacity to care for their child and parenting stress can exacerbate psychotic symptoms.

Keywords Psychosis · Parenting · Qualitative · Thematic analysis · Expressed emotion

Highlights

- This paper investigated the expressed emotion of parents with psychosis, and found that, generally, parents displayed high levels of warmth.
- This paper also investigated the needs and experiences of parents with psychosis using qualitative methods.
- Psychosis can impact on the parent's capacity to parent, and many parents were reluctant to talk about psychosis with their children.
- The stress from parenting was described by some parents as a trigger for their psychosis.
- Participants described a need to feel normal, and suggested that peer support would be beneficial.

Psychosis is characterised by positive symptoms of hallucinations and delusions, negative symptoms of reduced motivation and pleasure, and disturbances of language and cognition. These symptoms are found in various psychotic disorders, including schizophrenia, schizophreniform disorder, schizoaffective disorder, brief psychotic disorder and other psychotic disorder (American Psychiatric Association, 2013). More than a third of individuals with a diagnosed psychotic condition are also a parent (Campbell et al., 2018; Hearle et al., 1999; Schrank et al., 2016).

Being responsible for a child as well as managing psychotic symptoms presents extra challenges on top of those that are already integral to parenting. For example, being preoccupied and distressed by positive symptoms of psychosis, plus managing the sedating side effect of medication, may mean these parents are less attuned and responsive to the

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needs of their children, which can lead to withdrawn or intrusive parental interactions (Johnson et al., 2018; Oyserman et al., 2005; Stein et al., 2009). If parents are experiencing acute psychosis, the content of their hallucinations or delusions may involve their children, making it a possibility that parents cannot provide a safe environment for children at those times (Gearing et al., 2012; Seeman, 2002; Snellen et al., 1999). Negative symptoms can also reduce parental responsiveness, as parents can lack the motivation to engage fully with their children and to respond in a timely and appropriate way to their children's needs (Seeman, 2015). Cognitive symptoms can involve problems with attention and of understanding children's mental states, affecting parental responsiveness even in the absence of psychotic symptoms, in addition to difficulties with planning, which is a skill that is often needed by parents (Campbell & Poon, 2020).

However, acute psychotic symptoms are often brief, and a reduction in these is associated with improved quality of parenting care (Kahng et al., 2008). In fact, the quality of parenting provided by those who have experienced psychosis can often depend on the severity of the illness (Radley et al., 2021; Røhder et al., 2019). For example, a diagnosis of schizophrenia necessitates the presence of symptoms for at least six months (American Psychiatric Association, 2013), and has been associated with higher social services involvement and poorer staff-rated assessment of parenting amongst parents with a diagnosis of a psychotic disorder (Howard et al., 2004). Furthermore, an earlier onset of psychotic symptoms and a longer duration of illness are also associated with a reduced quality of parenting care in this population (Abel et al., 2005; Campbell et al., 2018).

In turn, parenting is relentless and often stressful, and stress is known to exacerbate psychotic symptoms and contribute to relapse (Howes & Murray, 2014). In addition to the direct effects of psychotic symptoms on parenting, these parents and children are more likely to be affected by stigma (Vauth et al., 2007), poverty (Riebschleger, 2004; Werner et al., 2007), isolation (Dolman et al., 2013), unemployment (Owen et al., 2016) and the challenges associated with single parenthood (Howard et al., 2004). These wider environmental factors have been theorised to be even more detrimental to these families than the direct effects of a severe parental mental illness (Abel et al., 2005; Gladstone et al., 2011).

This study has two aims, firstly to investigate the expressed emotion of parents with psychosis towards their child, and secondly to understand the needs and experiences of parents with psychosis in regards to parenting during the acute and recovery phases of psychosis.

Expressed emotion (EE) is a construct used to measure the emotional climate within families, and assessment of EE was originally used as a way of classifying the attitudes of a patient's parent towards them (Brown et al., 1972). It was found that patients with psychosis whose families displayed high levels of criticism or hostility towards them were more likely to relapse (Hooley & Parker, 2006). This study will, instead, assess the EE of parents with psychosis in order to investigate each parent's attitudes towards their child. High levels of EE, such as criticism, hostility and emotional overinvolvement are related to poor life outcomes for children, including psychopathology (Peris & Miklowitz, 2015). EE has been shown to be a mediator of the relationship between parental mental illness and children's mental health (Uddin et al., 2021), making it an essential factor to address.

The Camberwell Family Interview (Vaughn & Leff, 1976) is the gold standard assessment of EE, but requires formal training and takes one to two hours to administer. A quicker way of assessing EE is to use a speech sample, where family members are asked to speak about their child for a few minutes. Sentences are then coded for elements of EE such as warmth, criticism, and emotional overinvolvement (Hooley & Parker, 2006). We used Caspi et al. (2004) method of eliciting a speech sample containing EE, since other methods require the interviewer to remain silent and avoid eye-contact with the participant (Magaña et al., 1986), which seemed inappropriate for this study's sample. This method of assessing EE is more simplistic since it only measures warmth, negativity, positive comments, and negative comments, and has been found to be associated with observed parent-child interactions (Weston et al., 2017).

Qualitative work to date has tended to focus across conditions, grouping together parents with any type of severe mental illness (Ackerson, 2003; Perera et al., 2015; Stallard et al., 2004). The symptoms of psychosis are distinct from those of other severe mental illnesses. The nature of psychosis means that, although there are times when these parents relapse and may become acutely unwell, the most acute stages typically last only a few weeks, and these are followed by periods of remitted or attenuated symptoms that last for months or years (Schizophrenia Commission, 2012). Therefore, in order to support parents with psychosis, it is important to understand this population's specific parenting experiences and needs. When parents who have experienced psychosis are the focus of qualitative research, it is often mothers with postpartum psychosis who are interviewed (e.g. Edwards and Timmons, 2005; Robertson & Lyons, 2003; Wan et al., 2008), who will have different needs to parents who may have developed a psychotic disorder later in life (Mowbray et al., 2005).

Previous qualitative research conducted with parents with severe mental illness has highlighted parental stress and worry about the ways in which their symptoms may affect their children (Dolman et al., 2013; Ueno & Kamibeppu, 2012), as well as parents' anxiety regarding potential loss of custody (Ackerson, 2003; Dolman et al., 2013). Parents with mental illness also report struggling with knowing what to tell their children about their illness and

how to protect them (Maybery et al., 2005; Stallard et al., 2004; Strand et al., 2020). Qualitative research also suggests that parenting is a source of pride and is a valued role in these parents' lives (Ackerson, 2003).

This study is one of the first to focus specifically on the needs and experiences of parents with psychosis, rather than parents with severe mental illness in general. It also investigates the needs of both mothers and fathers. While mothers with severe mental illness have traditionally been the focus of this research, fathers with severe mental illness have described similar levels of anxiety about, and pride in, parenting (Evenson et al., 2008; van der Ende et al., 2016).

Methods

The study was given ethical approval by South Central Oxford C Research Ethics Committee.

Design

Individual interviews were carried out with parents who had a diagnosis of any psychotic disorder, and who had a child between the ages of three and eleven years. This qualitative study was underpinned by a grounded theory approach in which the research was data-driven (Glaser et al., 1968), such that there was a simultaneous, rather than linear, process of data collection and analysis. Reflexive thematic analysis was used in order to establish patterns of meaning in the data (Braun & Clarke, 2006, 2020). The study used previous findings with similar populations as a springboard for question formation, such as Dolman et al.'s (2013) meta-synthesis of qualitative work with parents with severe mental illness, while also aiming to build on and extend that body of work.

The interview was person-centred, whereby the interviewer probed any topics raised by the participant. Initial questions focused on how participants felt their symptoms affected their parenting, the stigma of having psychosis, confidence in parenting, and their relationship with their child. Findings from the data analysis guided the recruitment of the next participants and the content of the topic guide. For example, when it became clear that many participants had not disclosed details about their experiences of psychosis to their child, talking about psychosis with one's children was probed more in later interviews. Additionally, many of the initial participants independently raised the idea of a peer support programme with other parents, and this topic was also introduced in interviews with later participants.

Participants

Potential participants were recruited from Early Intervention in Psychosis services and Adult Mental Health Teams in Oxford Health NHS Foundation Trust. This study was presented to care coordinators in these teams. Care coordinators then asked eligible service users on their caseloads if they were happy to be contacted about a research study. If they were, a member of the research team contacted them and gave them the participant information sheet. Participants were given at least 24 hours to consider whether they wanted to take part or not. Before giving written informed consent to take part, participants were given the opportunity to ask any questions they had about the study.

Participants were eligible if they had a diagnosis of any psychotic disorder and were a parent of a child between the ages of three and eleven years old with whom they had at least ten hours of contact per week. Participants were still eligible if they had other children outside of this age range. This age range was chosen so that the research was addressing a stable period of parenting whereby the children of participants were pre-adolescent but participants would no longer see themselves as 'new' parents.

Procedure

All interviews took place between May and October 2019, and lasted between 45 and 75 minutes. In most cases the researcher travelled to the participant's home to conduct the interview, and some were conducted on Oxford Health NHS Foundation Trust sites. All the parents interviewed were outpatients. Each interview began with five questions formulated by Caspi et al. (2004) which are designed to rate the expressed emotion of parents towards their children. Parents were asked to answer these questions in relation to their eldest child within the age range of 3 to 11. These questions were:

1. I'd like to start off by just getting a general picture of [name]. Can you tell me a little about him/her?
2. What's [name] like, say in comparison with other children the same age?
3. In what ways would you like him/her to be different?
4. How do you feel when [name] is away from you?
5. How do you feel about [name] when you take him/her out in public?

After parents had answered these questions, the semi-structured interview began. Although participants may have had children outside of the study's age range, the interview focused on the experiences with their child(ren) who were aged three to eleven years old. The researcher followed a Distress and Safeguarding protocol during the study. Participants' care coordinators were informed that they had taken part in the study, and participants were compensated £10 for their time.

Analysis

Expressed emotion

Expressed emotion (EE) was coded according to Caspi's unpublished manual. JR and LJ completed the training detailed in this manual over one month. Five elements of expressed emotion were rated. First, participants' initial statement about their child was rated as positive, negative or neutral. Then the number of negative comments and positive comments were counted. Finally, warmth and negativity were rated on a scale of 0 to 5, which was a general assessment of the whole transcript, and negative and positive comments also contributed towards these ratings. This coding is detailed more fully in the manual.

JR and LJ rated each transcript separately and then the ratings were compared and any disagreements were resolved. The initial percent agreement was calculated by dividing the number of agreements by the number of total decisions. An agreement was defined as the two raters making the same decision or making a decision that was only one point away on the elements of the negative comments, positive comments and ratings of warmth and negativity. Disagreements were resolved through discussion; for numbers of negative and positive comments, most disagreements related to counting similar comments more than once. These results were collated and interpreted qualitatively.

Qualitative interviews

The audio recorded interviews were transcribed either by the researcher or a transcription service. Following transcription, reflexive thematic analysis as described by Braun and Clarke (2006, 2020) was used to generate themes in the parent interviews. The researcher familiarised herself with the transcription by reading it, and listening to it closely, while making initial notes. Then salient elements of the document were coded using NVivo 12 software. Each code captured one meaningful observation from the data. Coding started immediately after the first interview had been conducted.

Once the researcher had coded six transcribed interviews, the researcher started to develop initial themes and subthemes. Further transcripts were then coded to see whether this initial analysis was appropriate and whether any new concepts were identifiable. This process was repeated until the codes and themes were deemed to describe all twelve transcripts. The codes and themes were checked iteratively during their development at meetings with the primary researcher's supervisors.

Member checking is a process in qualitative research whereby the researchers' analysis is presented to, and discussed with, the original participants to avoid misrepresentation of participants' views, and to enhance authenticity (Braun & Clarke, 2013). The results from this study were presented to and discussed with a group of four mothers with psychosis in November 2019, three of whom had taken part in the study.

Reflexivity statement

In qualitative research, it is important to acknowledge the researcher's role in conducting the research and shaping the analysis. Although the primary researcher did not reveal any information about her age or mental health, participants likely assumed she was childless and had not experienced psychosis.

Sensitive content of the interviews included possible involvement with social services and risk to self or children. A Distress and Safeguarding protocol was designed for the researcher to follow if any safeguarding concerns arose or if the participant became noticeably distressed at any point during the interview. No current safeguarding or risk issues presented themselves. One participant later revealed during participation in another study with the researcher that she had been paranoid during the interview, which led to her being less candid about her experiences than she might have been if she were interviewed again.

Findings

Demographics

Twelve participants took part, ten mothers and two fathers (see Table 1). The majority of participants had only experienced one episode of psychosis. Eleven parents lived with their children, and one did not.

Expressed Emotion

Table 2 describes each participant's expressed emotion towards their eldest child within the study's age range. The participants generally expressed high levels of warmth and low levels of negativity towards their child. Half of the participants did not have any negative comments recorded. Two participants (P06 and P12) displayed low levels of both warmth and negativity and one participant displayed high levels of negativity (P07). Examples of comments are listed in Table 3. The percent agreement for each element of expression emotion is recorded in Table 2. The total percent agreement was 81.7%.

Thematic Analysis

Four themes were developed: (1) the impact of psychosis on parenting, (2) the need to protect their child, (3) the need to

Table 1 Demographics of participants

ID	Gender	Age	Ethnicity	Marital status	Years since first psychotic episode	Number of hospital admissions due to psychosis	Number of children	Child genders
P01	Female	40–49	White British	Married	3	0	2	1M 1F
P02	Female	40–49	White British	Divorced	2	0	3	2M 1F
P03	Female	30–39	White British	Single	3	1	1	1F
P04	Male	50–59	Black British	Married	1	1	1	1F
P05	Female	40–49	White British	Married	0	0	2	2M
P06	Female	30–39	Black British	Married	0	1	2	2M
P07	Female	30–39	White British	Separated	2	0	3	3M
P08	Male	50–59	White (other)	Married	15	2	1	1M
P09	Female	30–39	White British	Single	5	0	3	3M
P10	Female	40–49	Black British	Single	33	4	1	1F
P11	Female	30–39	White British	Single	1	1	1	1M
P12	Female	20–29	Asian British–Pakistani	Married	12	2	1	1M

feel normal, and (4) the impact of parenting stress on psychosis (see Fig. 1). These results demonstrate that parents have a desire to protect their child by keeping psychosis hidden, that parents need to feel normal as a response to the stigma from psychosis, as well as how the difficulties of parenting and the symptoms of psychosis impact on one another in a cyclical manner. These themes are further described by subthemes.

Theme 1: The Impact of Psychosis on Parenting

The first theme describes the impact of the most severe period of psychosis on participants' capacity to look after their children and the impact on their children.

Impact on parenting capacity

During an acute episode of psychosis, some parents spoke about being able to provide for the practical needs of their children, but felt themselves to be lacking when it came to looking after them emotionally: *"Looking back I don't know how but I did. I always managed to feed them and bath them, but their emotional needs I wasn't able to give them back then"* (P09). Parents described feeling too overwhelmed to concentrate on their child's demands in addition to experiencing psychotic thought processes: *"I was just lost in this weird train of thought and he would be going 'mum mum mum' and I wouldn't even be listening"* (P02); *"You can't be a proper parent because you're constantly worrying"* (P11). One mother described being in a state of such panic that she was not able to get her child to school or was *"so fatigued that even having a shower took all my energy. I'd do one thing and then I'd have to go and lay down"* (P02).

Some participants had experienced a more severe episode of psychosis which required a period of hospitalisation. These parents described how their psychotic episode was so all-consuming that not only was it not possible to function as a caregiver for someone else, it was difficult even to care for themselves: *"And I couldn't be a parent… I couldn't be a mum. I wasn't capable. I literally was not capable of being a parent because I was so ill"* (P07). For one mother, who had experienced psychosis since the age of 13, her child lived with his father and she was resigned to the fact that she could not be his caregiver simply saying: *"I've got mental health issues so I can't look after him"* (P12).

Parents also described how they developed poor coping strategies such as using alcohol or drugs to numb the psychotic experience, rendering them further incapable of care: *"I couldn't function and it was getting worse and worse. I wasn't really dealing with [child's name]. I was drinking a bottle of wine in the evening because it numbed my brain. It was the only time that I felt like I had any kind of release from it I suppose"* (P02). Two mothers described having attempted suicide during the most severe period.

Content of symptoms focused on parenting

A number of participants described how, during an acute psychotic phase, the content of their psychotic symptoms was focused on parenting, and some parents spoke about

Table 2 Expression emotion of each participant

ID	Initial Comment	Number of negative comments	Number of positive comments	Warmth (0–5)	Negativity (0–5)	Total length of EE section (time in minutes and seconds)
P01	Neutral	2	3	4	1	6:48
P02	Neutral	4	5	4	2	3:36
P03	Neutral	3	3	3	3	4:20
P04	Positive	0	9	5	0	7:02
P05	Positive	0	9	5	0	10:35
P06	Neutral	0	1	2	0	2:25
P07	Negative	5	0	1	4	4:47
P08	Positive	0	3	4	0	2:59
P09	Neutral	0	1	3	0	3:07
P10	Positive	0	2	4	1	12:12
P11	Neutral	6	1	3	3	4:16
P12	Neutral	1	1	2	1	2:02
Average	Neutral	1.75	3.17	3.33	1.25	5:21
Percent agreement	83.3%	75%	66.6%	91.7%	91.7%	*N/A*

Table 3 Examples of positive and negative comments

Negative comments	P02: If he doesn't want to do something he can be quite difficult
	P03: She's quite a challenging child
	P07: He feels the need sometimes, which is very infuriating, to take control
	P07: He used to be lovely not so much now
	P11: He can be very hard work
Positive comments	P02: Generally he's lovely
	P04: When I walk in the public I'm proud of her because that's when I see her behaviour
	P05: I wouldn't change absolutely anything about him. He's a wonderful kid
	P10: She is very understanding and she is very caring
	P11: He's a lovable little boy

having acted on persecutory beliefs when interacting with their children.

One mother described how she felt she was being judged as a parent during an acute episode of psychosis. She explained her auditory hallucinations as messages coming into her head that gave her instructions on how to be a better parent: "*It was testing me to see what I would notice. Would I notice the lights? And then I heard my little boy come through singing… but I was tested. And it was about being a good parent really"* (P05).

Other participants described how they had felt that they needed to protect their children when experiencing paranoid beliefs. A father talked about how fearful he was that his family was in danger: *"I went to tell them… that someone is coming. 'There's people coming.' I scared them"* (P04). A mother spoke about how she felt her whole family was being monitored through mobile phones and the TV: *"I used to say, 'let me see your tablet or let me see your phone' because I wanted to check what was on it"* (P09). Another mother refused to take her child out of the house because she was worried that he was in danger: *"But I just didn't want to take him out and I wanted to keep him safe, I didn't want him to get any bugs or anything"* (P11).

Impact on child

Parents described being aware of the impact that their psychosis had on their children, particularly when the children had witnessed them acting on their fears of persecution. Parents described how they had scared their children: *"I smashed some plates and things. Afterwards he was a bit jumpy about me being in the kitchen. If I accidentally dropped something he'd sort of say 'What was that? What was that?'"* (P02).

One mother who had been admitted to hospital described how this had impacted on her child's behaviour when she returned home: *"When I came out I kind of let him get away with murder because I felt bad because I wasn't around. And he did change with that because like I said he got very, very clingy"* (P11). Parents of older children spoke about how they were embarrassed to remember that their child needed to care for them during this period of illness, and one mother said that she still relied on her daughter to help her manage medication: *"She always tells me, 'mummy*

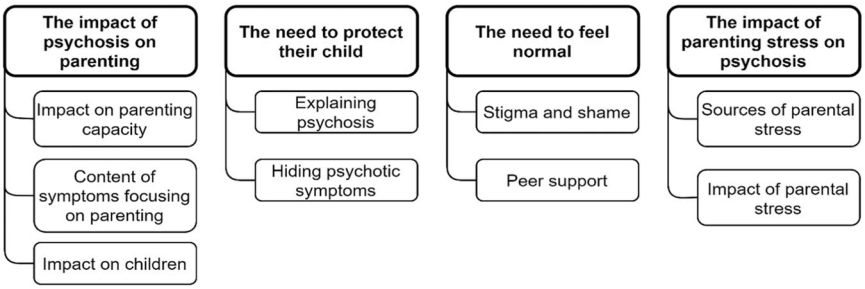

Fig. 1 Themes and subthemes

have you taken your medication' and I feel so emotional like you know" (P10).

However, some parents highlighted a number of positives of their children not seeing them at their best: "*They've realised that, you know, mum's not superwoman and that everyone's kind of a bit fallible"* (P02).

Theme 2: The Need to Protect their Child

This theme describes how all parents demonstrated a wish to protect their children in how much they explained about psychosis, and the extent to which they tried to keep their symptoms hidden from their children.

Explaining psychosis

When parents were asked about the extent of their child's awareness about their mental health problems, and how much they would want them to know, a range of views was expressed. Most views were connected with an underlying concern about wanting their child to be protected from the full extent of their psychosis. Many parents were concerned with trying to keep a sense of normality in their child's life. They wanted to protect their children from being worried and experiencing further hurt: *"I'm trying to give them as normal a life as possible and you know, I would rather keep it to myself and not worry them if I don't need to worry them"* (P09); *"It was a very hard point in their lives. And I don't want to hurt them any more than they've already been hurt by it"* (P07).

Efforts to explain their mental health to children did not focus explicitly on psychosis and parents referred to talking to their children on a 'need-to-know' basis, whereby they would not volunteer information until they were asked: *"When they're ready to ask me questions about when mummy was ill then I'll quite happily answer their questions without holding anything back but I won't bring it up openly and say 'right well I want to talk to you about this'"* (P07). Interestingly, parents often commented that they felt their children were not aware or curious about this issue, and that, if psychosis was explained to them, they would not understand it: *"I don't think it would impact them to know it was psychosis, you know. They wouldn't understand"* (P05).

Hiding psychotic symptoms

The interviews suggested that some parents believed that their children had limited awareness of what their parent had experienced; they felt that their children were not always aware that the behaviour their parent exhibited was connected to their mental health: *"But they don't see most of my anxiety. The most they see is when I'm pacing up and down"* (P09).

Most parents wanted to keep their full experience of psychosis hidden from their children, and this was especially true for those with younger children. One mother described how she would say to her son that she felt *"'a bit tired today' so we'll maybe we'll have a more relaxing chill out day. Maybe we'll watch a film or something. But I don't say I'm depressed or I'm exhausted or I can't actually move off the sofa which is what I wanna say"* (P02). A parent who had managed his psychosis for a decade before having children spoke about how he would seek hospital admission more quickly now that he had a son: *"Well, I try to protect him from these things so this is why if I had the same problem I'd go straight to hospital"* (P08). This father also had told his child that he was working abroad, when in reality, he was admitted to hospital following a relapse.

Theme 3: The Need to Feel Normal

The third theme describes how many participants had faced stigma as a result of psychosis. Participants described how despite the stigma they had experienced, they were just like any other parent. Participants wanted to reassure themselves of their capability and the importance of peer support in doing this was identified.

Stigma and shame

The stigma experienced by these parents due to their psychosis was evident in many of the participants, some of whom described having been made to feel unwelcome by other parents who had learned of their diagnosis: *"Other mums*

don't really understand and I think they get a bit scared by it" (P03). When they alluded to what they believed others thought of them, they used words like 'psycho', 'nutter', 'bonkers', 'crazy': *"Not many people know about psychosis because, I think, when you use the word 'psychosis' people think of a psycho 'oh she's a complete psycho cos she's got psychosis'"* (P02). This stigma had seemingly resulted in participants choosing to use euphemisms to describe their experience of psychosis to their friends and family, such as 'ill', 'bit tired' or 'mental breakdown'.

Parents spoke about being criticised or treated badly, and a number of examples were given of negative interactions with the police and with social services: *"My sister turned up with my mum and then the next thing I knew the police were here beating the living daylights out of me"* (P11); *"Social services have been a big one. Not the last social services lady, cos she was lovely, but the one before that was horrific, and she gave me a really hard time. And was really quite horrible to me, and yeah I could have really have done without her"* (P02).

Parents asserted their normality, and spoke about having 'normal mum worries' and living a 'normal life': *"Well now I say 'that was the past and like I said, you know, I'm back to normal.' It was a thing that happened"* (P04). One mother described how she had started to regain confidence in her parenting ability: *"No I am confident. I'm a good parent. I'm starting to believe it more. Yeah. I am. I have been a really good parent"* (P05).

Peer support

Participants explained that no-one ever truly understood what it is like to go through a psychotic episode unless they had been through one themselves: *"You can't really talk about psychosis with anyone else because no-one really understands"* (P02).

When asked about what would help, a recurring answer was a peer support programme. Parents wanted coping strategies, advice, and to meet someone who had also experienced psychosis *"to know that you're not alone"* (P11). Parents felt that talking to someone who understood *"makes you feel more normal"* (P05). One mother explained that *"if you talked in a group setting with other parents, where they understood what psychosis was, and you could share different experiences, and then maybe share things that have worked, and then also it's then sociable as well, and you may gain, sort of, friends out of it"* (P02).

Theme 4: The Impact of Parenting Stress on Psychosis

The fourth theme describes how participants reported frequent stressful experiences of parenting and how these stresses subsequently impacted them in many ways, and for some may have triggered a psychotic episode. This theme resonated much more strongly with some participants than others, in particular the mothers in the sample.

Sources of parental stress

Participants described having had an overly idealistic view of parenting which inevitably failed to meet their expectations: *"You think it is all going to be cuddles and little booties and you don't take into consideration the constant sleepless nights, the pain, the illnesses, the worry"* (P07). Many of the children in the sample had additional needs such as autism or ADHD, which increased the stress that these parents experienced: *"She would hit me, kick me, bite me, pull my hair because she was so frustrated that she couldn't tell you what she wanted"* (P01); *"So he can't express himself particularly well and he was biting my arm and kicking… you know it's physical and a rage"* (P05).

Many of the participants were single parents, and described feeling lonely and without anyone to rely on: *"And bedtime is actually the thing that I find the hardest cos she's quite tricky at bedtime. And there's sometimes where I've been stood outside her room just crying thinking 'I just wish there was somebody here who could go through it with me and me not have to do it on my own'"* (P03). Even where participants did have a partner, some were often doing the bulk of the parenting, leaving them effectively with sole parental responsibility: *"You haven't got somebody there to say 'I will help you. I will help you get your child ready. I will help you do this.' You haven't got that option cos there's nobody else there so you have to carry on parenting as well as being very ill"* (P01); *"I've not got that support there so if it happens again I can't just go and phone someone and say, 'come and get him I'm not feeling very well', because I know no one would come"* (P11).

There was also some evidence that these parents experienced high levels of stress from parenting in general: *"When I get a phone call from the school, I answer the phone as quickly as I can. And it's normally because he's been naughty, or he's done something bad but I'm constantly worried like oh my god, what if he's had an accident and I've got to get to him?"* (P11).

Impact of parental stress

For some participants, parenting stress appeared to be a trigger for psychosis. One of these participants explained why parenting was so stressful for her: *"My life is my children so if anything's going wrong with them it's my fault"* (P05). Another mother described her particular difficulties getting her 10-year-old child to go to bed and how this meant her sleep was disrupted every night. This in turn, was one of her main triggers for psychosis: *"The original*

problem was lack of sleep because she does not sleep and when you go to bed, half the time, I didn't want to go to bed because I knew that I'd be up most of the night" (P01).

Other aspects of parenting were also identified by some as the trigger for a psychotic episode such as fatigue from childcare, feeling unprepared to become a parent, lack of sleep, and stress around children's behaviour. The stress of single parenthood also had a significant impact on some participants: *"Being ill as the sole provider is a total nightmare and it used to give me sleepless nights"* (P02).

However, it should be noted that not all participants identified parenting-related triggers, and a range of other triggers were referenced including drug-use, death of a family member, lack of sleep due to working hours, a volatile family life and abuse from a partner.

Discussion

Key Findings

This study assessed the expressed emotion and conducted a thematic analysis of interviews with parents who had experienced psychosis. Alongside Gregg et al. (2021), this is one of the first studies to focus explicitly on the expressed emotion of parents with psychosis towards their children. The results suggest that the majority of participants demonstrated high levels of warmth towards their child, with half of parents not expressing a single negative comment about their child. Two parents (P06 and P12) had a short interview, and displayed an overall lack of positivity or negativity in terms of the emotions expressed towards their child. This may be due to diminished emotional expression, a negative symptom of psychosis, which includes reduced verbal expression. Although the positive symptoms of psychosis are more often highlighted when discussing the impact of psychosis on families, negative symptoms will impact on parents' emotional availability for their children (Seeman, 2015; Valiakalayil et al., 2004). Only one parent in the sample (P07) was found to express any notable negativity towards their child and it was clear from her interview that she had faced many parenting difficulties and a high level of involvement from social services.

Due to the qualitative design of this study, it is not possible to draw any comparisons between its findings and those from other studies. When compared to controls, parents with mental health difficulties often display higher expressed emotion. For example, mothers who score higher on measures of depression have been found to be more hostile and emotionally over-involved with their children (Bolton et al., 2003; Peters et al., 2005) and parents with psychosis have been shown to display more criticism and hostility (Gregg et al., 2021).

Four themes were developed from the data from the in-depth interviews with parents. Parents described how experiencing psychosis had affected them and their family. Positive psychotic symptoms made parents feel that they could not look after themselves or their children, which is consistent with the findings from other qualitative work with this population (Jungbauer et al., 2010; Strand & Rudolfsson, 2020).

In periods of symptomatic stability, parents referred to the need to mitigate stigma and restore their self-confidence, and they identified the potential benefit of peer-support in achieving this. Parents stressed their need to protect their children from the symptoms that they were experiencing and also from knowing about their condition. While parents also suggested that their children did not want information about their psychosis, there is a large literature demonstrating that children of parents with mental illness do want to understand their parent's mental health difficulties (Gladstone et al., 2011; Wahl et al., 2017). This discrepancy may reflect the fact that the children of the parents in the current study were young compared to most research which has been carried out with older children, or it may be the case that these parents are underestimating their children's need for information.

Some parents spoke about how parenting stress was a trigger for psychosis, and this was particularly true for the women in the sample who were more likely to report having parenting-related stress, and were more likely to be a single parent or perform the majority of parenting tasks. People with psychosis have poor social networks (Gayer-Anderson & Morgan, 2013) and are more often single (Perälä et al., 2008) compared to those without a psychiatric diagnosis. Single parents face all the challenges of parenthood, without much respite or being able to share parenting tasks. They are often more likely to struggle with finances and are less likely to receive social support compared to dual parent families (Taylor & Conger, 2017). For the mothers in this sample it seemed that the stress they experienced from parenting was exacerbated by undertaking almost the entire parenting role on their own.

The two themes 'the impact of psychosis on parenting' and 'the impact of parenting stress on psychosis', indicate a cyclical relationship between parenthood and the experience of psychosis. Parents with psychosis often report that their children have emotional and behavioural difficulties (Gregg et al., 2021; Stallard et al., 2004) and it is well-established that stress plays an important role in triggering psychotic symptoms (Klippel et al., 2017; Myin-Germeys & van Os, 2007). Whereas most research with parents with psychosis is focused on the impact of psychosis on families (e.g. Strand et al., 2020), it is essential that the converse relationship is also considered.

The majority of qualitative work conducted with parents experiencing a mental health problem focuses on mothers

(Dolman et al., 2013), but the few qualitative studies that focus on fathers have found that fatherhood is an important part of their identity, that they experience anxiety about custody loss, and describe a lack of support for fathers with a mental health condition (Evenson et al., 2008; Reupert & Maybery, 2009). In the current study, the two fathers in the sample emphasised their role as the head of the family and the pride they felt in being a father.

The experience of stigma is a common theme in qualitative research with parents with mental illness (Dolman et al., 2013). Parents in this study had been stigmatised by friends and professionals and many had experienced shame from psychosis which had resulted in parents lacking confidence in their parenting ability. Many parents suggested the idea of a peer support programme in order to share experiences and get advice from someone with personal experience of psychosis. Parent peer supports may be uniquely situated to provide parents with psychosis with practical and emotional support by sharing advice and alleviating stigma (Nicholson & Valentine, 2019).

Strengths and Limitations

A strength of this study is that the interpretation of the data from the parents' interviews was checked for authenticity with a group of four parents with psychosis in November 2019. The group discussion demonstrated that, on the whole, the parents agreed with the results from the thematic analysis. It also resulted in more emphasis being brought to certain areas of the analysis such as the importance of peer support.

One limitation of this study is the measure of expressed emotion that was used, which to the authors' knowledge has not been validated. With more time and resources, it would have been preferable to measure expressed emotion using the Camberwell Family Interview (Vaughn & Leff, 1976).

Another limitation of this study is that participants were primarily mothers who had experienced only one episode of psychosis, and therefore, the themes from this study may not be representative of all parents with psychosis. It is clear from previous research that mothers and fathers with psychosis have diverging needs (Evenson et al., 2008), and the theme 'the impact of parenting stress on psychosis' from the thematic analysis was more clearly an issue for the mothers in the sample than fathers. Furthermore, most participants were recruited from an Early Intervention in Psychosis service, meaning their experience of psychosis was relatively recent. This likely added more emphasis to the theme of stigma and more discussion around the initial trigger for psychosis. Similarly, it would have been informative to include more parents who had lived with psychosis before they had become a parent. The inclusion of more male participants and more participants from Adult Mental Health Teams would have allowed any differences with regard to these factors to be explored further.

Implications for Practice and Future Research

While the impact of parental psychosis on parents (Strand et al., 2020; van der Ende et al., 2014) and children (Fudge & Mason, 2004; Rasic et al., 2014) is well documented, the impact of parenting stress on psychosis has not been widely addressed to date even though it is well known that stress can exacerbate psychotic symptoms (Klippel et al., 2017; Myin-Germeys & van Os, 2007). The parents interviewed seemed to experience high amounts of stress from parenting which may contribute to their psychotic relapses and in some cases may have contributed to the onset of their first episode of psychosis. Furthermore, many of the parents lacked social support systems, with the result that they did not have support to alleviate stressful parenting experiences. The relationship between stress from parenting and psychotic symptoms as well as other moderating variables, such as child's behaviour, social support, parenting self-confidence, should be investigated further.

Much research on parental psychosis has focused on child outcomes (e.g. Johnson et al., 2018; Riches et al., 2019; Somers, 2007; Strand & Meyersson, 2020), and there is currently a lack of evidence regarding the needs of the parents themselves. This study has shown that parents with psychosis have specific needs, one of the most salient being the need for peer support. Future research should further investigate the specific social, psychological, and parenting needs that parents who have experienced psychosis may have, and which factors lead to more positive outcomes for the parents in order to design effective methods of support.

Conclusions

This study interviewed ten mothers and two fathers with a diagnosis of a psychotic disorder. It assessed the expressed emotion of parents with psychosis towards one of their children and found that the sample, in general, expressed high levels of warmth overall. It also demonstrated, however, the potential impact of the negative symptoms of psychosis. The thematic analysis described the impact of the acute positive symptoms of psychosis on both the parent and the child, and how parents wanted to protect their children and feel normal despite experiencing an episode of psychosis. Importantly, the results from the thematic analysis highlighted the cyclical nature of the relationship between parenting and psychosis, whereby the symptoms can affect parenting capacity, and in turn how parenting stress can heighten psychotic symptoms and contribute to relapse. Further research is needed to explore this relationship between stress from parenting and the occurrence of psychotic experiences.

Data Availability

The data that support the findings of this study are available on request from the corresponding author J.R. The data are not publicly available as they contain information that could identify the research participants.

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Compliance with Ethical Standards

Conflict of Interest The authors declare no competing interests.

Ethics Approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by South Central Oxford C Research Ethics Committee.

Informed Consent Informed consent was obtained from all individual participants included in the study and participants gave consent regarding publishing quotations from their interviews.

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