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# Living with Psychosis without Mental Health Services: A Narrative Interview Study

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experiences”

## Abstract

### *Objectives*

Little research has looked at how people experience psychosis who do not use mental health services. The present study aimed to explore the recovery narratives of people with psychosis who have neither sought nor received support from mental health services for at least five years.

### *Design*

A narrative interview study. Thematic analysis was used to analyse the data.

### *Setting*

United Kingdom

### *Participants*

Twenty-eight participants with self-defined psychotic experiences were asked to provide a free narrative about their experiences.

### *Results*

Five themes were identified: 1) Perceiving psychosis as positive, as specific view of experiences; 2) Making sense of psychotic experiences, as a more active psychological process to find explanations and meaning; 3) Finding sources of strength, mainly in relationships and the environment, but outside services; 4) Negative past experiences of mental health services, leading to disengagement; and 5) Positive past experiences with individual clinicians, as an appreciation of individuals despite negative views of services as a whole.

### *Conclusions*

Perceiving psychosis as something positive, a process of making sense of psychotic experiences and the ability to find external sources of strength all underpin – in addition to negative experiences with services - a choice to live with psychosis outside of services. Future research may explore to what extent these perceptions, psychological processes and abilities can be facilitated and strengthened, in order to support those people with psychosis who do not seek treatment and possibly also some of those who are in treatment.

### *Strengths and limitations of this study*

- This study is one of the first studies to explore the experiences of people with psychosis outside services who are hard to reach and commonly not included in research studies.
- A free narrative approach emphasised the perspective of the interviewees and allowed for rich material to be analysed.
- The findings show distinct positive ways of perceiving and explaining psychotic experiences and of finding sources of strengths
- The sample was heterogeneous in terms of biographies and living situations, but it was a convenience sample and exclusively from England.
- The study did not entail formal diagnostic assessments.

## 1. Introduction

Research has shown that a considerable number of people with psychosis do not present to mental health services.[1] One review patients with in the general population estimated that 7% of children and adults are likely to have psychotic experiences in their lifetime.[2] Other reviews estimate voice-hearing prevalence at 13%[3] and experience of paranoia up to 30%.[4] Since these rates are much higher than the numbers of patients with psychosis in health services[5], many people with such experiences are likely to live with and manage their experiences without conventional treatment or other support from mental health services.

There is a debate as to whether the psychosis-like experiences in the general population are qualitatively distinct from those in clinical populations.[6,7] Peters and colleagues (2016)[8] found that both clinical and non-clinical groups with psychotic experiences experienced positive symptoms. The non-clinical group had lower levels of paranoia, delusions, cognitive difficulties and negative symptoms, but more somatic or tactile hallucinations.

Studying the experiences of people with psychosis outside services can be challenging, as many people in such situations may avoid not only contact with health services, but also participation in research studies. However, such research may: identify different strategies for living with psychosis than those found in clinical samples; point towards forms of support that are appropriate for people with psychosis who do not seek treatment; and provide evidence on attitudes, skills and resources that can promote

1  
2  
3 recovery also in other groups.[9] Against this background, the current study aimed to  
4  
5 explore the experiences and views of people with psychotic experiences who have not  
6  
7 received any treatment or other support from mental health services for the past five  
8  
9 years.  
10  
11  
12

## 13 14 **2. Methods**

### 15 16 17 18 **2.1 Participants**

19  
20  
21  
22  
23 Participants met the following inclusion criteria: having had self-defined experiences of  
24  
25 what could be termed psychosis (with examples given of hearing voices or seeing or  
26  
27 believing things that others do not), not having accessed mental health services for the  
28  
29 previous five years although they may have had accessed them earlier (i.e. secondary or  
30  
31 tertiary mental health services in the categorisation of the National Health Service in the  
32  
33 United Kingdom), over 18, and able to give informed consent. Recruitment activities  
34  
35 were structured and iteratively refined to seek a maximum variation sample of psychosis  
36  
37 experiences.[10] They took place through: primary care (general practitioner practices)  
38  
39 services in London, online support groups or networks (e.g. spiritual or critical  
40  
41 psychiatry networks), presentations and attendance at groups affiliated to the Hearing  
42  
43 Voices Network, and advertising via charity and non-governmental organisations.  
44  
45  
46  
47  
48  
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50

### 51 52 **2.2 Procedure**

53  
54 Twenty-eight semi-structured interviews were conducted by three researchers (RM, ZJ  
55  
56 and JLB) over a 15-month period, with most interviews (n=25) carried out by RM. Most  
57  
58 interviews were conducted in London, with some in other parts of England. Each  
59  
60



1  
2  
3 participant took part in a 40-120 minutes interview conducted in health services or  
4  
5 community venues. The interviewer asked open-ended questions designed to elicit a  
6  
7 narrative,[11] with minimal or no interruption from the researcher in order to facilitate  
8  
9 fluent sharing of experiences.[12] A Lived Experience Advisory Panel advised on the  
10  
11 content and conduct of the interview.  
12  
13  
14  
15

### 16 17 **2.3 Analysis**

18  
19 Interviews were audio-recorded, transcribed verbatim, anonymised, and were then  
20  
21 transferred to NVivo 11 for data management and analysis. An initial inductive thematic  
22  
23 analysis was conducted to identify key themes across the interviews, based on an  
24  
25 approach outlined by Braun and Clarke (2006).[13] A preliminary coding framework  
26  
27 was established from this analysis in relation to the research question, and refined  
28  
29 through discussion in the wider research team, from backgrounds in clinical and  
30  
31 academic psychiatry and clinical and academic psychology. Transcripts were then  
32  
33 analysed in more detail by two members of the research team, with 20% being double  
34  
35 coded and checked for consistency by two independent researchers. The overall  
36  
37 concordance rate was 96.6%. Discrepancies were discussed until resolved. Coding  
38  
39 consisted of identification and allocation of text relating to the preliminary coding  
40  
41 framework, allowing comparison of themes occurring within and across sources. Once all  
42  
43 transcripts were analysed, the lead author synthesised the coding into themes with the  
44  
45 two analysts, continually returning to the data to maintain reflexivity. Regular  
46  
47 discussions were held between all analysts to adapt and develop the coding framework,  
48  
49 which underwent several iterations from its original form to the final version.  
50  
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## 2.4 Ethics

This research was undertaken as part of the NIHR Narrative Experiences Online (NEON) study (ISRCTN11152837, information at <http://www.researchintorecovery.com/neon>) between March 2018 and August 2019. Ethical Committee approval was obtained in advance (Nottingham 2 REC 17/EM/0401). All participants provided written informed consent.

## 3. Results

### 3.1 Sample

Twenty-eight people with self-defined psychotic experiences were interviewed between February 2018 and May 2019. Eleven were recruited via primary care practices and 17 through alternative networks and advertising. Sixteen were female, and 11 male (1 preferred not to say). Four participants reported being in the age group of 25-34 years; 6 in the group of 35-44 years; 9 in the group of 45-54 years; 4 in the group of 55-64 years; and 2 being more than 64 years of age (1 preferred not to say). Eighteen self-declared ethnicity as White, 2 as Asian, and 5 as Black (3 preferred not to say).

### 3.2 Themes

Five distinct themes were identified.

#### 3.2.1 *Perceiving psychosis as positive*

A large proportion of participants perceived their experience of psychosis as positive overall.

1  
2  
3 *"I think I have something extraordinary. And people with extraordinary things find it hard*  
4 *in society, and probably I don't find it hard' (A01)*  
5  
6  
7

8 For some, this related to seeing such experiences, e.g. their hallucinations, as a positive  
9 coping mechanism to deal with difficult life events, even if the hallucinations themselves  
10 could be difficult:  
11  
12  
13

14 *"...my brain was trying to process all the things happening around me, and tried to*  
15 *externalise it in some form that I could perhaps deal with a bit better..." (A27)*  
16  
17  
18

19 Others found their experiences educational or empowering, and were able to learn or  
20 gain new and positive perspectives from them:  
21  
22  
23

24 *"I kind of tried to get rid of all the negativity and then ended up getting like a higher kind of*  
25 *version of myself so I felt really empowered and really kind of connected to the universe"*  
26  
27  
28

29 (A02)

30 *"I feel that in that space I get some real truths" (A010)*  
31  
32  
33

34 For some, their psychosis had become a positive part of their identity, an essential part of  
35 how they saw themselves in the world, providing a resource that they could contribute:  
36  
37  
38

39 *"I have taken the only course open to me to cope with symptoms, that is to treat seeing*  
40 *things which are not there, or hearing what nobody else does, as attributes which in truth*  
41 *are a part of who I am and harnessing them as the strengths they really are, and the gifts*  
42 *which I have to give the world." (A19)*  
43  
44  
45  
46  
47

48 *"...in a way I see it as a positive, they don't have to be negative, you can actually accept*  
49 *who you are and.. you make the best of it really" (A020)*  
50  
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### 3.2.2 Making sense of psychotic experiences

When people managed to make sense of their psychotic experiences, this often also implied a positive view of the experiences. It was however not just a positive perspective of what happened. It often involved a more active psychological process of developing a meaningful explanation. An explanation for why they had experienced psychosis was important, and these explanations themselves became a significant part of their narratives.

*"I have since learnt that actually there is meaning to things and actually I am somebody that..does seem to have a perception or radar that not everybody seems to have..in one way the psychosis was awful, but in another way it exposed this horrible past that was unknown, unexplored, unexpressed" (A07)*

Many linked their experiences with negative life events, such as abuse in childhood or difficult upbringing:

*"...I've been a voice hearer and someone who hallucinates since I was little. ...the reason for that in my particular case is because I am a survivor of incest." (A05)*

*"...I come from a fairly dysfunctional family..It did actually take me years and years to put together the idea.... that the mental health problems sort of arose as..a means for my brain to externalise what was going on inside.. sometimes they (hallucinations) were more supportive than the people around me were.... maybe my brain created an enviroment for me..to be in..I understood better...I had control of" (A027)*

1  
2  
3 These negative experiences could be from a period before individuals were able to form  
4 memories, so that finding out about their past could make sense of their experiences:  
5

6  
7 *“And that's when I found out that we'd been separated when I was a very, very young baby...*  
8  
9 *...so you know and my soothing- self-soothing system probably wasn't that well developed,*  
10  
11 *so that helped me to understand” (A11)*  
12  
13  
14  
15

16  
17 Other negative experiences were from later in life:  
18

19 *“...my mental health challenges were triggered by having radical surgery. I mean it is - it is*  
20 *important to say this, so, before (the surgery) I hadn't experienced (mental health*  
21 *challenges)...” (A16)*  
22  
23  
24  
25  
26  
27  
28

29 Some attributed their experiences to spiritual reasons, finding them empowering and  
30 meaningful:  
31

32 *“This story is in my ancestry, that's my theory of what happened, I don't have any other*  
33 *explanation and I felt that there was- I felt that's what happened to me” (A10)*  
34  
35  
36  
37

38 These explanations were sometimes linked to religious beliefs:  
39

40 *“...as a Christian I don't see anything that ever happens to anybody as being a result of*  
41 *random chance anymore, I think it was important to my journey” (A22)*  
42  
43  
44  
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### 48 3.2.3 Finding sources of strength

49

50  
51 A third theme was the sources of strength that participants found around them, in  
52 relationships and in their natural environment, but outside of mental health services.  
53

54 These included both receiving and giving social support, and the validation and feelings  
55 of connection provided by others, particularly those with similar experiences:  
56  
57  
58  
59  
60

1  
2  
3 *"...it was amazing, we all kind of met up and we had all been through similar things, and it*  
4  
5 *was incredible to just hear everyone speak and be open"* (A02)  
6  
7

8 The significance of social support was also expressed in terms of the importance of close  
9  
10 personal relationships:

11  
12 *"Well I think my partners have been too important in my life. So the first time when I got*  
13  
14 *my diagnosis I was with my boyfriend... at that time he was very, very, very supportive and*  
15  
16 *so was his family."* (A09)  
17  
18

19 Some people spoke about the importance of taking ownership of their narrative for their  
20  
21 recovery, creating a coherent sequence of events, often through counselling or  
22  
23 alternative therapy work:

24  
25  
26 *"...part of the reason I find narrative therapy actually so interesting as an approach is that*  
27  
28 *part of the recovery process has been assembling the story. And understanding it as a story."*  
29  
30  
31 (A06)  
32  
33

34 Others found the process of creating a written narrative cathartic:

35  
36 *"...I wrote my autobiography so that was a big part of my healing process, it was- It was a*  
37  
38 *catharsis I needed to look back and understand my journey... that... was a huge part of my*  
39  
40 *healing process."* (A11)  
41  
42

43 For some, opposing the dominant illness model of psychosis and using spiritual or other  
44  
45 alternative frameworks to make sense of their experiences was essential to being well:

46  
47  
48 *"...going into the different reality... and taking it seriously rather than dismissing it as*  
49  
50 *illness was my recovery, that was what helped me to recover, I think."* (A10)  
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3 Many people spoke about the importance of self-care in managing their mental health,  
4 and finding ways to improve their wellbeing on a daily basis. For example, people found  
5 exercise and healthy eating to be helpful:  
6  
7  
8

9  
10 *"I started to exercise, and I'd started to clean up my food, and I started to do a bit of*  
11 *meditation.... And I said, oh, wow, this is how you get better then."* (A16)  
12

13  
14 Other forms of self-care mentioned were making time and space for oneself, and  
15 spending time in nature:  
16  
17  
18

19 *"I love the sea, every time I feel like anxious and nervous I just look at the sea and it is just,*  
20 *like, beautiful."* (A02)  
21  
22

23  
24 Another helpful factor people spoke about was finding purpose in daily life, and  
25 productive ways to use their time. These could entail creative outlets such as music and  
26 art forms:  
27  
28  
29

30 *"...it's recovery through my artwork every day... - I think the art has given me great kind of*  
31 *great kind of structure..."* (A01)  
32  
33

34  
35 For others, purpose was achieved by engaging in or returning to higher education or  
36 seeking to educate themselves:  
37  
38  
39

40 *"...it was important to me sort of coming back to schooling, that was... unfinished business*  
41 *because I could never go..."* (A04)  
42  
43

44  
45 Others found purpose in voluntary or paid employment:  
46  
47

48 *"...the job that I do is what keeps me out of hospital, I know it yeah, and it has done for all*  
49 *that time because I haven't been hospitalised..."* (A12)  
50  
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### 3.2.4 Negative past experiences of mental health services

Some participants had previously engaged with services, and several ones of them reported negative experiences of treatments, and of interactions with staff, which contributed to their decision to disengage from health services. These could relate to unwanted medication side effects:

*"The medication didn't help at all, actually it numbed me so much that I had no point any more"* (A04)

But also to coercive and forceful treatment by staff:

*"I remember they were dragging me up the ward... to the seclusion room, where they monitored me...they were very, very forceful and all I said was I just need your help and.....it wasn't really dealt with, no-one answered back, that was the process."* (A021)

*"The regime was punitive...if you...stepped out of line... the notion was you would receive more intensive care which of course was nonsense, it was a form of punishment."* (A020)

And indeed abuse, as reported by two participants:

*"Unfortunately I was raped in hospital and it made it - made it very uncomfortable to be there so I left really quickly."* (A03)

*"...when I was sectioned um in the local mental health hospital I was raped, probably by staff, which added to my trauma..."* (A05)

### 3.2.5 Positive past experiences with individual clinicians

However, past experiences with services were mixed. Those people who reported positive experiences often referred to the importance of helpful relationships with



1  
2  
3 individual clinicians, rather than a team or a whole service, so that these positive  
4  
5 interactions did not provide a motivation to re-engage with the service. The individual  
6  
7 clinicians made them feel “heard”, and were able to see them as a whole person as  
8  
9 opposed to the sum of their symptoms:  
10  
11

12 *“When I said to him (psychiatrist), he said 'tell me about yourself' I said 'there it is, read*  
13 *this' he pushed my file away and said 'that's a piece of paper- it tells me nothing about you'*  
14 *and then we connected, we clicked” (A17)*  
15  
16  
17  
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19  
20  
21

22 Others spoke about clinicians who did not discount the validity of their experiences and  
23  
24 their potential meaning, respecting their interpretations of experiences:  
25  
26

27 *“...I had a couple of sessions with a psychiatrist... ..and I actually said to him 'do you think*  
28 *it's possible to see, like have an episode like a psychotic episode and in that episode literally*  
29 *see the things that you're going to experience in your life all in that episode and then*  
30 *everything actually begin very, very slowly' and he said 'it's possible, you know.'” (A08)*  
31  
32  
33  
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38 Even participants with negative views of services as a whole, tended to distinguish  
39  
40 between individual clinicians. The participant who criticised a punitive regime in the  
41  
42 previous theme also remarked:  
43  
44  
45

46 *“I thought the psychiatrist was very pleasant, we had some interesting chats...(after*  
47 *leaving)..I felt the loss of the attention of the psychiatrists..” (A020)*  
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#### 4. Discussion

We explored the narratives of people living with psychotic experiences, who have neither sought nor received any support from mental health services in the last five years. The focus was on understanding how people describe their views and experiences when not receiving treatment or any other type of help from mental health professionals. Five themes were identified in the narratives. Three themes reflect views and abilities that may be essential for the participants' choice for not contacting services. They include a positive perception of psychotic experiences even if they are seen as unusual, an active and – at least in parts – successful search for sense and meaning, and a link with the external world in form of finding strength in personal and natural sources around them. Two further themes address the past experiences with services, which were often negative but also involved helpful relationships with individual clinicians.

##### *Strengths and limitations*

Whilst numerous studies have investigated how patients with diagnosed psychotic disorders experience and are satisfied or dissatisfied with the treatment they have been receiving in mental health services, this is one of the first studies to explore the narratives of a hard-to-reach population of people with experiences of psychosis who have not received any treatment or other support from such services. The methodological approach of encouraging people to tell their story in a free narrative emphasised the perspective of the interviewees and allowed for rich material to be analysed. We recruited from different groups, and reached saturation for generating the main themes.

The study also has several limitations. Firstly, we recruited a convenience sample. Given that there may be very different groups of people with the experience of psychosis who

1  
2  
3 do not use mental health services, other samples may have yielded a different picture.  
4  
5 Secondly, but overall too small to analyse differences between subgroups. Thirdly, the  
6  
7 approach of a free narrative limited the option to focus on specific aspects in more depth  
8  
9 and detail. And finally, neither did the interviewers conduct a formal diagnostic  
10  
11 assessment nor did they check the diagnostic assessment of possible treatment episodes  
12  
13 in the past. Thus, one may question to what extent experiences of the interviewees would  
14  
15 be classified as psychosis if such formal assessments had been made.  
16  
17  
18  
19

### 20 *Comparison against the literature*

21  
22  
23 A previous study investigating the experiences of people with psychotic symptoms not  
24  
25 accessing mental health services[14] found themes relating to self-care and the  
26  
27 importance of underlying explanatory framework. Similarly, two themes in this study  
28  
29 centre on the importance of individuals' positive perceptions of their experiences and of  
30  
31 finding a meaningful explanation. Perceiving psychotic experiences as meaningful and  
32  
33 related to their life situation has been shown to be beneficial for people's prospects of  
34  
35 recovery.[15]□  
36  
37  
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42 The findings suggest that it is important that people's explanations are aligned with and  
43  
44 accepted by others, as well as containing personal meaning. An aspect of helpful social  
45  
46 support was sharing a joint explanatory model for their experiences, and receiving  
47  
48 validation of these beliefs. In addition, we found that individual relationships with  
49  
50 clinicians could be particularly helpful when individuals felt that they were listened to,  
51  
52 and their explanations were taken seriously. This is in line with previous research  
53  
54 showing that sharing the same explanatory model for psychosis is associated with  
55  
56 improved treatment satisfaction and therapeutic relationship in outpatients diagnosed  
57  
58  
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1  
2  
3 with schizophrenia[16] and more generally with a large body of evidence showing the  
4 importance of the direct communication between patients and individual clinicians.[17] 2

7 The importance of establishing a positive patient-clinician relationship through  
8 appropriate communication is underlined by the fact that many participants still  
9 expressed their appreciation for individual clinicians, although these relationships had  
10 ceased at least five years before and although all participants had decided not seek help  
11 from mental health services in general anymore.

21 Many of the participants believed that specific traumatic experiences had played a causal  
22 role in the development of psychotic experiences. Previous narrative reviews and meta-  
23 analyses have suggested a link between traumatic experiences and psychosis[18-  
24 20],which may be influenced by lower psychosocial functioning and greater social  
25 adversity.[8] 2

33 Having social connections was considered helpful not only in relation to the validation of  
34 explanatory models, but also for daily support and wellbeing, which is consistent with  
35 research showing the important role of social networks for recovery. [21,22] In addition,  
36 people spoke about the importance of being engaged in occupations, religious groups and  
37 creative activities. Such activities may provide purpose and structure. [23] Structure and  
38 using various forms of self-care to stay well have been found to be associated with larger  
39 social networks.[24] 2

54 That people who prefer not to be in contact with services report a range of negative past  
55 experiences with services is not surprising. That negative experiences can lead to

1  
2  
3 disengagement has been shown before [25] and may be seen as obvious. Some people  
4  
5 reported indeed extreme stressful events such as being raped which can easily be  
6  
7 understood as a reason to avoid any contact with service from then onwards. Overall,  
8  
9 however, the negative reports about experiences with services were not more  
10  
11 pronounced than in some studies with people who are still - or again - in  
12  
13 treatment.[25,26] Explanatory models for their experiences that are not shared, the  
14  
15 feeling not be listened to and not to be treated with respect, and further stressful events  
16  
17 during treatment, particularly on wards, are frequently found in accounts of patients who  
18  
19 are in care of mental health services too .[27,28] Moreover, people in this study  
20  
21 repeatedly described very positive experiences with individual clinicians although this  
22  
23 did not generalise to positive views of the services as a whole. Thus, one may speculate as  
24  
25 to whether the negative experiences reported in this study are rather common and  
26  
27 possibly less important than the positive views and resources for the decision not to seek  
28  
29 treatment and for the ability to manage psychotic experiences outside services. Seeing  
30  
31 psychotic experiences – for various reasons - as something positive, making sense of the  
32  
33 experiences and finding external sources of strength might be more specific for this  
34  
35 group of people than the critical views of health services.  
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### 45 *Conclusions*

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49  
50 It remains an open question as to whether any and, if so, how many of the interviewees  
51  
52 might actually have benefitted from whatever support mental health services in the given  
53  
54 area can provide. Services that accommodate and respect a range of explanatory models  
55  
56 and have clinicians with good communication skills who treat patients with interest and  
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3 respect should be more likely to maintain helpful relationships even with people who  
4  
5 have different explanations for their experiences. This might even outweigh some  
6  
7 negative treatment experiences that many patients might have at some stage of their  
8  
9 long-term pathways.  
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15 A challenge for future research is to explore whether it is possible to facilitate and  
16  
17 strengthen the positive perceptions, psychological processes and abilities to find strength  
18  
19 in engaging with external sources, that were identified in this study. Such research might  
20  
21 lead to a better support for people with psychosis who do not seek treatment. It might  
22  
23 also benefit the further development of approaches for people with psychosis who are in  
24  
25 treatment, as it could help their recovery although in some patients it might also  
26  
27 undermine the motivation to stay in treatment.  
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34  
35  
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37  
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39  
40 authors and not necessarily those of the NIHR.  
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### 46 **A competing interests statement**

47  
48  
49 The authors have no conflicts of interest to disclose.  
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### 53 **Contribution**

54  
55  
56 All of the co-authors have contributed towards drafting the manuscript and have  
57  
58 approved the final version of it.  
59  
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4 **Patient and Public Involvement**  
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6 A Lived Experience Advisory Panel advised on the content and conduct of the interview.  
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**SRQR****Item 1 – Yes – Page 1****Item 2 – Yes – Page 2 to 3****Item 3 – Yes – Page 4 to 5****Item 4 – Yes – Page 5****Item 5 - Yes – Page 5 to 6****Item 6 – Yes – Page 6****Item 7 – Yes – Page 6****Item 8 – Yes – Page 5 to 6****Item 9 – Yes – Page 6****Item 10 – Yes – Page 5 to 6****Item 11 – Yes – Page 5 to 6****Item 12 – Yes – Page 7****Item 13 – Yes – Page 6****Item 14 – Yes – Page 6****Item 15 – Yes – Page 6****Item 16 - Yes – Page 7 to Page 14****Item 17 – Yes - Page 7 to Page 14****Item 18 – Yes – Page 15 to 18****Item 19 – Yes – Page 15 to 16****Item 20 -Yes – Page 19****Item 21 – Yes – Page 19**

# BMJ Open

## Living with Psychosis without Mental Health Services: A Narrative Interview Study

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<b>Primary Subject Heading</b>:	Mental health
Secondary Subject Heading:	Qualitative research
Keywords:	QUALITATIVE RESEARCH, Adult psychiatry < PSYCHIATRY, PSYCHIATRY

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4 1 Living with Psychosis without Mental Health Services: A Narrative  
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7 2 Interview Study  
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10 3 Rose McGranahan<sup>1</sup>, Zivile Jakaite<sup>1\*</sup>, Alice Edwards<sup>2</sup>, Stefan Rennick-Egglestone<sup>3</sup>, Mike  
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31 Keywords: “recovery”; “hearing voices”; “schizophrenia”; “qualitative”; “psychotic  
32 experiences”  
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1  
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3 35 **Abstract**

4 36

5 37 *Objectives*

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7  
8 38 Little research has looked at how people who do not use mental health services  
9  
10 39 experience psychosis. Thus, the present study aimed to explore the experiences and  
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12 40 views of people with psychosis who have neither sought nor received support from  
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14 41 mental health services for at least five years.  
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18 42 *Design*

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21 43 A narrative interview study. Thematic analysis was used to analyse the data.  
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24 44 *Setting*

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27 45 United Kingdom  
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30 46 *Participants*

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33 47 Twenty-eight participants with self-defined psychotic experiences were asked to  
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35 48 provide a free narrative about their experiences.  
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39 49 *Results*

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42 50 Five themes were identified: 1) Perceiving psychosis as positive 2) Making sense of  
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44 51 psychotic experiences as a more active psychological process to find explanations and  
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46 52 meaning; 3) Finding sources of strength, mainly in relationships and the environment,  
47  
48 53 but outside of services; 4) Negative past experiences of mental health services, leading  
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50 54 to disengagement; and 5) Positive past experiences with individual clinicians, as an  
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52 55 appreciation of individuals despite negative views of services as a whole.  
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3 57 *Conclusions*  
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6 58 Perceiving psychosis as something positive, a process of making sense of psychotic  
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8 59 experiences and the ability to find external sources of strength all underpin – in addition  
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11 60 to negative experiences with services - a choice to live with psychosis outside of  
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13 61 services. Future research may explore to what extent these perceptions, psychological  
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15 62 processes and abilities can be facilitated and strengthened, in order to support those  
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17 63 people with psychosis who do not seek treatment and possibly also some of those who  
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19 64 are in treatment.  
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26 66 *Strengths and limitations of this study*  
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- 29 67 - This study is one of the first to explore the experiences of people with psychosis  
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31 68 outside of services who are hard to reach and commonly not included in  
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33 69 research studies.  
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35 70 - A free narrative approach emphasised the perspective of the interviewees and  
36  
37 71 allowed for rich material to be analysed.  
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39 72 - The participants included in this study were recruited from a wide-range of  
40  
41 73 organisations and geographical areas within the United Kingdom, thus enabling a  
42  
43 74 maximum variation within the target population.  
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45 75 - The sample was heterogeneous in terms of biographies and living situations, but  
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47 76 it was a convenience sample and exclusively from England.  
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49 77 - The study did not entail formal diagnostic assessments.  
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## 80 1. Introduction

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82 Research has shown that a considerable number of people with psychosis do not present  
83 to mental health services.[1] According to one review, 7% of the general population are  
84 likely to have psychotic experiences in their lifetime.[2] Other reviews estimate voice-  
85 hearing prevalence at 13%[3] and experience of paranoia in up to 30% of the general  
86 population.[4] Since these rates are much higher than the numbers of patients with  
87 psychosis in health services[5], many people with such experiences are likely to live with  
88 and manage their experiences without conventional treatment or other support from  
89 mental health services.

90  
91 There is a debate as to whether the psychosis-like experiences in the general population  
92 are qualitatively distinct from those in clinical populations.[6,7] Peters and colleagues  
93 (2016)[8] found that both clinical and non-clinical groups with psychotic experiences  
94 experienced positive symptoms. Interestingly, the non-clinical group had lower levels of  
95 paranoia, delusions, cognitive difficulties and negative symptoms, but more somatic or  
96 tactile hallucinations.

97  
98 Previous literature exploring the views of people with psychotic-like experiences who do  
99 not seek support from mental health services is scarce. To our knowledge, one prior  
100 study conducted by Boumans and colleagues (2017) [9] documented two key factors in  
101 maintaining wellbeing without having to access mental health services: personalised self-  
102 care and adoption of interpretive frameworks (in order to fully make sense of psychotic  
103 experiences).

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3 104 Studying the experiences of people with psychosis outside of services can be  
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5 105 challenging, as many people in such situations may avoid not only contact with health  
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7 106 services, but also participation in research studies. However, such research may:  
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9 107 identify different strategies for living with psychosis than those found in clinical  
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11 108 samples; point towards forms of support that are appropriate for people with psychosis  
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13 109 who do not seek treatment; and provide evidence on attitudes, skills and resources that  
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15 110 can promote recovery also in other groups.[10] Against this background, the current  
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17 111 study aimed to explore the experiences and views of people with psychotic experiences  
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19 112 who have not received any treatment or other support from mental health services for  
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21 113 the past five years.  
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## 115 **2. Methods**

### 116 **2.1 Study Design**

117 We conducted qualitative semi-structured narrative interviews. The narrative  
118 methodological approach was chosen as it enables a flexible collection of rich material  
119 whilst simultaneously placing emphasis on the perspective of the interviewees. [11] A  
120 Lived Experience Advisory Panel advised on the content and conduct of the interview,  
121 including the phrasing of questions and the terminology used in the interviews.  
122 As per the ethics application, the study had a pre-defined sample size of up to 30  
123 participants. It was agreed that participant recruitment would be terminated after data  
124 saturation was reached.  
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## 128 2.2 Participants and Recruitment Activities

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130 Participants met the following inclusion criteria: having had self-defined experiences of  
131 what could be termed psychosis (with examples given of hearing voices or seeing or  
132 believing things that others do not), not having accessed mental health services for the  
133 previous five years although they may have had accessed them earlier (i.e. secondary or  
134 tertiary mental health services in the categorisation of the National Health Service in the  
135 United Kingdom), over 18, and able to give informed consent.

136

137 Recruitment activities were structured and iteratively refined to seek a maximum  
138 variation sample of psychosis experiences. [12] To achieve a maximum variation sample  
139 of psychosis experiences, participants from a wide range of organisations and  
140 geographical areas (in and outside of London) were recruited. The recruitment of  
141 participants took place through: primary care (general practitioner practices) services  
142 in London, online support groups or networks (e.g. spiritual or critical psychiatry  
143 networks), groups affiliated to the Hearing Voices Network, and charity and non-  
144 governmental organisations. It is important to highlight that the organisations included  
145 in the current study do not provide specialist mental health treatment or support.  
146 Although the recruitment method varied slightly depending on the site being recruited  
147 from, in most instances the recruitment was facilitated by presentations and attendance  
148 at a variety of groups, advertising online or sending invitation letters to potential  
149 participants.

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3 151 Researchers explained the details of the study on the phone with potential participants,  
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5 152 and encouraged them to ask any questions or raise concerns. This was followed by a  
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7 153 meeting in person, in which individuals could make their final decision as to whether to  
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9 154 take part in the research interview. All participants received a participant information  
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11 155 sheet and were given a sufficient amount of time to consider whether to participate in  
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13 156 the study. As part of the recruitment process, all of the eligibility criteria were discussed  
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15 157 with each participant to verify that they were being met. There was no prior  
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17 158 relationship between the researchers conducting the interviews and the study  
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20 159 participants.  
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27 161 **2.3 Procedure**  
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29 162 Twenty-eight semi-structured interviews were conducted by three researchers (RM, ZJ  
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31 163 and JLB) over a 15-month period, with most interviews (n=25) carried out by RM. Most  
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33 164 interviews were conducted in London, with some in other parts of England. Each  
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35 165 participant took part in a 40-120 minute interview conducted in health services or  
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37 166 community venues. On the day of the interview, researchers provided the potential  
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39 167 participants with an in-depth explanation of the study procedures and aims, ensuring  
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41 168 their full understanding and ability to provide informed consent. During the interviews,  
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43 169 the researchers asked open-ended questions designed to elicit a narrative, [13] with  
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45 170 minimal or no interruption from the researcher in order to facilitate fluent sharing of  
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47 171 experiences.[14] Specifically, participants were asked to share their recovery story,  
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49 172 followed by some questions focusing on participants' experiences of sharing their  
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51 173 recovery story with others. All participants were reimbursed for their participation.  
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## 176 **2.4 Analysis**

177 Interviews were audio-recorded, transcribed verbatim, anonymised, and were then  
178 transferred to NVivo 11 for data management and analysis. After the researchers  
179 familiarised themselves with the content of the data, an initial inductive thematic  
180 analysis was conducted to identify key themes across the interviews, based on an  
181 approach outlined by Braun and Clarke (2006).[15] Preliminary codes were  
182 established from this analysis in relation to the research question, and refined through a  
183 continuous discussion in the wider research team, from backgrounds in clinical and  
184 academic psychiatry and clinical and academic psychology. Transcripts were then  
185 analysed in more detail by two members of the research team, with 20% being double  
186 coded and checked for consistency by two independent researchers. Discrepancies were  
187 discussed until resolved. Coding consisted of identification and allocation of text  
188 relating to the preliminary coding framework, allowing comparison of themes occurring  
189 within and across sources. Once all transcripts were coded, the lead author synthesised  
190 the coding into themes with the two analysts. Regular discussions were held between all  
191 analysts to adapt and develop the themes, which underwent several iterations from its  
192 original form to the final version. The researchers maintained reflexivity by consistently  
193 having discussions within the team and with the wider research group to gain a more  
194 varied perspective. Reflexive field notes were also utilised which focused on the  
195 researcher's role as an interviewer, including their feelings, possible biases and  
196 immediate context prior to the interview in order to further ensure reflexivity.

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## 200 **2.5 Ethics**

201 This research was undertaken as part of the NIHR Narrative Experiences Online (NEON)  
202 study (ISRCTN11152837, information at <http://www.researchintorecovery.com/neon>)  
203 between March 2018 and August 2019. Ethical Committee approval was obtained in  
204 advance (Nottingham 2 REC 17/EM/0401). All participants provided written informed  
205 consent.

206

## 207 **Patient and Public Involvement**

208 A Lived Experience Advisory Panel advised on the content and conduct of the interview.

209

210

## 211 **3. Results**

### 212 **3.1 Sample**

213 Twenty-eight people with self-defined psychotic experiences were interviewed between  
214 February 2018 and May 2019. The duration of the interviews ranged from 40 to 120  
215 minutes. Eleven participants were recruited via primary care practices and 17 through  
216 alternative networks and advertising. Sixteen were female, and 11 male (1 preferred not  
217 to say). Four participants reported being in the age group of 25-34 years; 6 in the group  
218 of 25-44 years; 9 in the group of 45-54 years; 4 in the group of 55-64 years; and 2 being  
219 more than 64 years of age (1 preferred not to say). Eighteen self-declared ethnicity as  
220 White, 2 as Asian, and 5 as Black (3 preferred not to say).

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3 227 **3.2 Themes**  
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5 228 Five distinct themes were identified.  
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10 230 *3.2.1 Perceiving psychosis as positive*  
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12 231 A large proportion of participants perceived their experience of psychosis as positive  
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15 232 overall.  
16

17 233 *"I think I have something extraordinary. And people with extraordinary things find it hard*  
18

19 234 *in society, and probably I don't find it hard'* (A01)  
20  
21

22 235 For some, this related to seeing such experiences, e.g. their hallucinations, as a positive  
23  
24

25 236 coping mechanism to deal with difficult life events, even if the hallucinations themselves  
26  
27

28 237 could be difficult:  
29

30 238 *"...my brain was trying to process all the things happening around me, and tried to*  
31

32 239 *externalise it in some form that I could perhaps deal with a bit better..."* (A27)  
33  
34

35 240 Others found their experiences educational or empowering, and were able to learn or  
36  
37

38 241 gain new and positive perspectives from them:  
39

40 242 *"I kind of tried to get rid of all the negativity and then ended up getting like a higher kind of*  
41

42 243 *version of myself so I felt really empowered and really kind of connected to the universe"*  
43

44 244 (A02)  
45

46 245 *"I feel that in that space I get some real truths"* (A010)  
47

48 246 For some, their psychosis had become a positive part of their identity, an essential part of  
49  
50

51 247 how they saw themselves in the world, providing a resource that they could contribute:  
52

53 248 *"I have taken the only course open to me to cope with symptoms, that is to treat seeing*  
54

55 249 *things which are not there, or hearing what nobody else does, as attributes which in truth*  
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3 250 *are a part of who I am and harnessing them as the strengths they really are, and the gifts*  
4  
5  
6 251 *which I have to give the world.” (A19)*

7  
8 252 *“...in a way I see it as a positive, they don't have to be negative, you can actually accept*  
9  
10 253 *who you are and.. you make the best of it really” (A020)*

11  
12  
13 254

### 15 255 3.2.2 *Making sense of psychotic experiences*

17  
18 256 When people managed to make sense of their psychotic experiences, this often also  
19  
20 257 implied a positive view of the experiences. It was, however, not just a positive  
21  
22 258 perspective of what happened. It often involved a more active psychological process of  
23  
24 259 developing a meaningful explanation. Indeed, the process of making sense of the  
25  
26 260 psychotic experiences was also often linked to the biographical context of the individual.  
27  
28 261 An explanation for why they had experienced psychosis was important, and these  
29  
30 262 explanations themselves became a significant part of their narratives.

31  
32 263 *“I have since learnt that actually there is meaning to things and actually I am somebody*  
33  
34 264 *that..does seem to have a perception or radar that not everybody seems to have..in one*  
35  
36 265 *way the psychosis was awful, but in another way it exposed this horrible past that was*  
37  
38 266 *unknown, unexplored, unexpressed” (A07)*

39  
40  
41 267 Many linked their experiences with negative life events, such as abuse in childhood or  
42  
43 268 difficult upbringing:

44  
45 269 *“...I've been a voice hearer and someone who hallucinates since I was little. ...the reason for*  
46  
47 270 *that in my particular case is because I am a survivor of incest.” (A05)*

48  
49 271 *“...I come from a fairly dysfunctional family..It did actually take me years and years to put*  
50  
51 272 *together the idea.... that the mental health problems sort of arose as..a means for my brain*  
52  
53 273 *to externalise what was going on inside.. sometimes they (hallucinations) were more*



1  
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3 274 *supportive than the people around me were.... maybe my brain created an enviroment for*  
4  
5 275 *me..to be in..I understood better...I had control of” (A027)*  
6  
7

8  
9 276 These negative experiences could be from a period before individuals were able to form  
10  
11 277 memories, so that finding out about their past could make sense of their experiences:

12  
13 278 *“And that's when I found out that we'd been separated when I was a very, very young baby...*  
14  
15 279 *...so you know and my soothing- self-soothing system probably wasn't that well developed,*  
16  
17 280 *so that helped me to understand” (A11)*

18  
19  
20 281 Other negative experiences were from later in life:

21  
22 282 *“...my mental health challenges were triggered by having radical surgery. I mean it is - it is*  
23  
24 283 *important to say this, so, before (the surgery) I hadn't experienced (mental health*  
25  
26 284 *challenges)...” (A16)*

27  
28  
29  
30 285 Some attributed their experiences to spiritual reasons, finding them empowering and  
31  
32 286 meaningful:

33  
34 287 *“This story is in my ancestry, that's my theory of what happened, I don't have any other*  
35  
36 288 *explanation and I felt that there was- I felt that's what happened to me” (A10)*

37  
38  
39 289 These explanations were sometimes linked to religious beliefs:

40  
41 290 *“...as a Christian I don't see anything that ever happens to anybody as being a result of*  
42  
43 291 *random chance anymore, I think it was important to my journey” (A22)*

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3 298 3.2.3 Finding sources of strength  
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6 299 A third theme was the sources of strength that participants found around them, in  
7  
8 300 relationships and in their natural environment, but outside of mental health services.

9 301 These included both receiving and giving social support, and the validation and feelings  
10  
11 302 of connection provided by others, particularly those with similar experiences:

12 303 *"...it was amazing, we all kind of met up and we had all been through similar things, and it*  
13  
14 304 *was incredible to just hear everyone speak and be open"* (A02)

15 305 The significance of social support was also expressed in terms of the importance of close  
16  
17 306 personal relationships:

18 307 *"Well I think my partners have been too important in my life. So the first time when I got*  
19  
20 308 *my diagnosis I was with my boyfriend... at that time he was very, very, very supportive and*  
21  
22 309 *so was his family."* (A09)

23 310 Some people spoke about the importance of taking ownership of their narrative for their  
24  
25 311 recovery, creating a coherent sequence of events, often through counselling or  
26  
27 312 alternative therapy work:

28 313 *"...part of the reason I find narrative therapy actually so interesting as an approach is that*  
29  
30 314 *part of the recovery process has been assembling the story. And understanding it as a story."*  
31  
32 315 (A06)

33 316 Others found the process of creating a written narrative cathartic:

34 317 *"...I wrote my autobiography so that was a big part of my healing process, it was- It was a*  
35  
36 318 *catharsis I needed to look back and understand my journey... that... was a huge part of my*  
37  
38 319 *healing process."* (A11)

39 320 For some, opposing the dominant illness model of psychosis and using spiritual or other  
40  
41 321 alternative frameworks to make sense of their experiences was essential to being well:

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3 322 *"...going into the different reality... and taking it seriously rather than dismissing it as*  
4  
5 323 *illness was my recovery, that was what helped me to recover, I think."* (A10)  
6  
7

8 324 Many people spoke about the importance of self-care in managing their mental health,  
9  
10 325 and finding ways to improve their wellbeing on a daily basis. For example, people found  
11  
12 326 exercise and healthy eating to be helpful:  
13

14  
15 327 *"I started to exercise, and I'd started to clean up my food, and I started to do a bit of*  
16  
17 328 *meditation.... And I said, oh, wow, this is how you get better then."* (A16)  
18

19 329 Other forms of self-care mentioned were making time and space for oneself, and  
20  
21  
22 330 spending time in nature:  
23

24 331 *"I love the sea, every time I feel like anxious and nervous I just look at the sea and it is just,*  
25  
26 332 *like, beautiful."* (A02)  
27

28  
29 333 Another helpful factor people spoke about was finding purpose in daily life, and  
30  
31 334 productive ways to use their time. These could entail creative outlets such as music and  
32  
33 335 art forms:  
34

35  
36 336 *"...it's recovery through my artwork every day... - I think the art has given me great kind of-*  
37  
38 337 *great kind of structure..."* (A01)  
39

40 338 For others, purpose was achieved by engaging in or returning to higher education or  
41  
42  
43 339 seeking to educate themselves:  
44

45 340 *"...it was important to me sort of coming back to schooling, that was... unfinished business*  
46  
47 341 *because I could never go..."* (A04)  
48

49  
50 342 Others found purpose in voluntary or paid employment:  
51

52 343 *"...the job that I do is what keeps me out of hospital, I know it yeah, and it has done for all*  
53  
54 344 *that time because I haven't been hospitalised..."* (A12)  
55

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3 346 3.2.4 Negative past experiences of mental health services  
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6 347 Some participants had previously engaged with services, and several of them reported  
7  
8 348 negative experiences of treatments and interactions with staff, which contributed to their  
9  
10 349 decision to disengage from health services. These could relate to unwanted medication  
11  
12 350 side effects:

13  
14  
15  
16 351 *"The medication didn't help at all, actually it numbed me so much that I had no point any*  
17  
18 352 *more"* (A04)

19  
20  
21 353 But also to coercive and forceful treatment by staff:

22  
23  
24 354 *"I remember they were dragging me up the ward... to the seclusion room, where they*  
25  
26 355 *monitored me...they were very, very forceful and all I said was I just need your help and.....it*  
27  
28 356 *wasn't really dealt with, no-one answered back, that was the process."* (A021)

29  
30  
31 357 *"The regime was punitive...if you...stepped out of line... the notion was you would receive*  
32  
33 358 *more intensive care which of course was nonsense, it was a form of punishment."* (A020)

34  
35  
36 359 And indeed abuse, as reported by two participants:

37  
38 360 *"Unfortunately I was raped in hospital and it made it - made it very uncomfortable to be*  
39  
40 361 *there so I left really quickly."* (A03)

41  
42  
43 362 *"...when I was sectioned um in the local mental health hospital I was raped, probably by*  
44  
45 363 *staff, which added to my trauma..."* (A05)

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3 369 3.2.5 Positive past experiences with individual clinicians  
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6 370 However, past experiences with services were mixed. Those people who reported  
7  
8 371 positive experiences often referred to the importance of helpful relationships with  
9  
10 372 individual clinicians, rather than a team or a whole service, so that these positive  
11  
12 373 interactions did not provide a motivation to re-engage with the service. The individual  
13  
14 374 clinicians made them feel “heard”, and were able to see them as a whole person as  
15  
16 375 opposed to the sum of their symptoms:  
17  
18  
19

20 376 *“When I said to him (psychiatrist), he said 'tell me about yourself' I said 'there it is, read*  
21  
22 377 *this' he pushed my file away and said 'that's a piece of paper- it tells me nothing about you'*  
23  
24 378 *and then we connected, we clicked” (A17)*  
25  
26

27 379 Others spoke about clinicians who did not discount the validity of their experiences and  
28  
29 380 their potential meaning, respecting their interpretations of experiences:  
30  
31

32 381 *“...I had a couple of sessions with a psychiatrist... ...and I actually said to him 'do you think*  
33  
34 382 *it's possible to see, like have an episode like a psychotic episode and in that episode literally*  
35  
36 383 *see the things that you're going to experience in your life all in that episode and then*  
37  
38 384 *everything actually begin very, very slowly' and he said 'it's possible, you know'.” (A08)*  
39  
40

41 385 Even participants with negative views of services as a whole, tended to distinguish  
42  
43 386 between individual clinicians. The participant who criticised a punitive regime in the  
44  
45 387 previous theme also remarked:  
46  
47

48  
49 388 *“I thought the psychiatrist was very pleasant, we had some interesting chats...(after*  
50  
51 389 *leaving)..I felt the loss of the attention of the psychiatrists..” (A020)*  
52  
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#### 392 4. Discussion

393

394 We explored the experiences and views of people living with psychotic experiences, who  
395 have neither sought nor received any support from mental health services in the last five  
396 years. The focus was on understanding how people describe their views and experiences  
397 when not receiving treatment or any other type of help from mental health professionals.  
398 Five themes were identified in the narratives. Three themes reflect views and abilities  
399 that may be essential for the participants' choice for not contacting services. They include  
400 a positive perception of psychotic experiences even if they are seen as unusual, an active  
401 and – at least in parts – successful search for sense and meaning, and a link with the  
402 external world in form of finding strength in personal and natural sources around them.  
403 Two further themes address the past experiences with services, which were often  
404 negative but also involved helpful relationships with individual clinicians.

#### 405 *Strengths and limitations*

406 Whilst numerous studies have investigated how patients with diagnosed psychotic  
407 disorders experience and are satisfied or dissatisfied with the treatment they have been  
408 receiving in mental health services, this is one of the first studies to explore the  
409 narratives of a hard-to-reach population of people with experiences of psychosis who are  
410 not in contact with mental health services. The methodological approach of encouraging  
411 people to tell their story in a free narrative emphasised the perspective of the  
412 interviewees and allowed for rich material to be analysed. We recruited from different  
413 groups, and reached saturation for generating the main themes.

414 The study also has several limitations. Firstly, we recruited a convenience sample. Given  
415 that there may be very different groups of people with the experience of psychosis who

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2  
3 416 do not use mental health services, other samples may have yielded a different picture.  
4  
5 417 Secondly, although the sample was selective, it was still heterogeneous in terms of  
6  
7 418 biographies and living situations. However, it was overall too small to analyse differences  
8  
9 419 between subgroups. Thirdly, the approach of a free narrative limited the option to focus  
10  
11 420 on specific aspects in more depth and detail. And finally, neither did the interviewers  
12  
13 421 conduct a formal diagnostic assessment nor did they check the diagnostic assessment of  
14  
15 422 possible treatment episodes in the past. Thus, one may question to what extent  
16  
17 423 experiences of the interviewees would be classified as psychosis if such formal  
18  
19 424 assessments had been made.  
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#### 25 425 *Summary of the results and comparison against the literature*

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28 426 A previous study investigating the experiences of people with psychotic symptoms not  
29  
30 427 accessing mental health services [9] found themes relating to self-care and the  
31  
32 428 importance of underlying explanatory frameworks. Similarly, two themes in this study  
33  
34 429 centre on the importance of individuals' positive perceptions of their experiences and  
35  
36 430 finding a meaningful explanation. Perceiving psychotic experiences as meaningful and  
37  
38 431 related to their life situation has been shown to be beneficial for people's prospects of  
39  
40 432 recovery. [16]

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44 433  
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46 434 The findings suggest that it is important that people's explanations are aligned with and  
47  
48 435 accepted by others, as well as contain personal meaning. An aspect of helpful social  
49  
50 436 support was sharing a joint explanatory model for their experiences, and receiving  
51  
52 437 validation of these beliefs. In addition, we found that individual relationships with  
53  
54 438 clinicians could be particularly helpful when individuals felt that they were listened to,  
55  
56 439 and their explanations were taken seriously. This is in line with previous research  
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3 440 showing that sharing the same explanatory model for psychosis is associated with  
4  
5 441 improved treatment satisfaction and therapeutic relationship in outpatients diagnosed  
6  
7 442 with schizophrenia[17] and more generally with a large body of evidence showing the  
8  
9 443 importance of the direct communication between patients and individual clinicians.[18]□  
10  
11 444 The importance of establishing a positive patient-clinician relationship through  
12  
13 445 appropriate communication is underlined by the fact that many participants still  
14  
15 446 expressed their appreciation for individual clinicians, although these relationships had  
16  
17 447 ceased at least five years before and all participants had decided not seek help from  
18  
19 448 mental health services in general anymore.  
20  
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24 449

25  
26 450 Many of the participants believed that specific traumatic experiences had played a causal  
27  
28 451 role in the development of psychotic experiences. Previous narrative reviews and meta-  
29  
30 452 analyses have suggested a link between traumatic experiences and psychosis [19–21],  
31  
32 453 which may be influenced by lower psychosocial functioning and greater social  
33  
34 454 adversity.[8]□  
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41 456 Having social connections was considered helpful not only in relation to the validation of  
42  
43 457 explanatory models, but also for daily support and wellbeing, which is consistent with  
44  
45 458 research showing the important role of social networks for recovery. [22,23] In addition,  
46  
47 459 people spoke about the importance of being engaged in occupations, religious groups and  
48  
49 460 creative activities. Such activities may provide purpose and structure. [24] Structure and  
50  
51 461 using various forms of self-care to stay well have been found to be associated with larger  
52  
53 462 social networks. [25]□  
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3 464 That people who prefer not to be in contact with services report a range of negative past  
4  
5 465 experiences with services is not surprising. Indeed, the fact that negative experiences can  
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7  
8 466 lead to disengagement has been shown before [26] and may be seen as obvious. Some  
9  
10 467 people reported extremely stressful events such as being raped which can easily be  
11  
12 468 understood as a reason to avoid any contact with services from then onwards. Overall,  
13  
14  
15 469 however, the negative reports about experiences with services were not more  
16  
17 470 pronounced than in some studies with people who are still - or again - in  
18  
19 471 treatment.[26,27] Explanatory models for their experiences that are not shared, the  
20  
21 472 feeling of not being listened to or treated with respect, and further stressful events  
22  
23 473 during treatment, particularly on wards, are frequently found in accounts of patients who  
24  
25 474 are in care of mental health services too.[28,29] Moreover, people in this study  
26  
27  
28 475 repeatedly described very positive experiences with individual clinicians although this  
29  
30 476 did not generalise to positive views of the services as a whole. Thus, one may speculate  
31  
32  
33 477 as to whether the negative experiences reported in this study are rather common and  
34  
35  
36 478 possibly less important than the positive views and resources in relation to the decision  
37  
38 479 not to seek treatment as well as the ability to manage psychotic experiences outside  
39  
40 480 services. Seeing psychotic experiences – for various reasons - as something positive,  
41  
42  
43 481 making sense of the experiences and finding external sources of strength might be more  
44  
45 482 specific for this group of people than the critical views of health services.  
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3 488 *Conclusions*  
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7  
8 490 Given a lack of previous literature, the current study sought to explore the experiences  
9  
10 491 and views of people with psychotic experiences who have neither sought nor received  
11  
12 492 support from mental health services for at least five years by employing a free narrative  
13  
14 493 interview methodology.  
15  
16

17 494

18  
19 495 However, it remains an open question as to whether any and, if so, how many of the  
20  
21 496 interviewees might actually have benefitted from whatever support mental health  
22  
23 497 services in the given area can provide. Services that accommodate and respect a range  
24  
25 498 of explanatory models and have clinicians with good communication skills who treat  
26  
27 499 patients with interest and respect should be more likely to maintain helpful  
28  
29 500 relationships even with people who have different explanations for their experiences.  
30  
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32  
33 501 This might even outweigh some negative treatment experiences that many patients  
34  
35 502 might have at some stage of their long-term pathways.  
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39  
40 504 A challenge for future research is to explore whether it is possible to facilitate and  
41  
42 505 strengthen the positive perceptions, psychological processes and abilities to find strength  
43  
44 506 in engaging with external sources, that were identified in this study. Such research might  
45  
46 507 lead to better support for people with psychosis who do not seek treatment. It might also  
47  
48 508 benefit the further development of approaches for people with psychosis who are in  
49  
50 509 treatment, as it could help their recovery although in some patients it might also  
51  
52 510 undermine the motivation to stay in treatment.  
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4  
5

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9 516

10  
11  
12 **517 A competing interests statement**  
13

14 518 The authors have no conflicts of interest to disclose.  
15 519

16  
17  
18 **520 Contribution**  
19

20  
21 521 SP designed the study and led the analysis, MS was in charge of the overall research  
22 522 programme and SE co-ordinated data collection across sites. The interviews were  
23 523 conducted by RM, ZJ and JLB, whilst all the transcripts were read by RM, ZJ, AE and SP.  
24 524 The analysis of the data and discussions regarding the codes/themes were undertaken  
25 525 by RM, ZJ, AE and SP. RM wrote the first draft of the manuscript. All of the co-authors  
26 526 have contributed towards revisions of the manuscript and have approved the final  
27 527 version of it.  
28  
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32 **530 Data Availability Statement**  
33

34 531

35 532 No additional data are available  
36 533

37 534

38 535

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40

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**SRQR**

**Item 1 – Title - Yes – Page 1; Lines 1-2**

**Item 2 – Abstract - Yes – Page 2-3; Lines 35-64**

**Item 3 – Problem Formulation -Yes - Page 4 to 5; Lines 83-113**

**Item 4 – Purpose or research question- Yes - Page 5; Lines 110-113**

**Item 5 - Qualitative Approach - Yes – Page 5; Lines 117-119**

**Item 6 – Researcher characteristics and reflexivity - Yes – Page 8; Lines 184; 192-196.**

**Item 7 – Setting/Site; Yes – Page 6; Lines 140-149**

**Item 8 – Sampling Strategy - Yes – Page 5-6; Lines 137-150.**

**Item 9 – Ethics - Yes – Page 9; Lines 200-205.**

**Item 10 – Data Collection Methods - Yes – Page 5 and 7; 168-173; 117-119.**

**Item 11 – Data Collection Instruments and Technologies- Yes – Page 5 and 7; 168-173; 117-119.**

**Item 12 – Units of Study –Page 6; Lines 130-135.**

**Item 13 – Data processing - Yes – Page 8; Lines 177-178**

**Item 14 – Data Analysis - Yes – Page 8; Lines 176-196.**

**Item 15 – Techniques used to enhance trustworthiness - Yes – Page 8; Lines 184-186.**

**Item 16 - Synthesis and interpretation - Yes – Pages 9-16; Lines 207-388.**

**Item 17 – Links to empirical data - Yes – Pages 10-16; Lines 226 – 388.**

**Item 18 – Integration with prior work, implications, transferability, and contribution(s) to the field  
Yes – Page 17 to 21 Lines 391-509.**

**Item 19 – Limitations - Yes – Pages 17-18; Lines 404-423.**

**Item 20 Conflicts of Interest -Yes – Page 22; Lines 516-517.**

**Item 21 Funding – Yes – Page 22; Lines 511-514.**

# BMJ Open

## Living with Psychosis without Mental Health Services: A Narrative Interview Study

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4 1 Living with Psychosis without Mental Health Services: A Narrative  
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7 2 Interview Study  
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10 3 Rose McGranahan<sup>1</sup>, Zivile Jakaite<sup>1\*</sup>, Alice Edwards<sup>2</sup>, Stefan Rennick-Egglestone<sup>3</sup>, Mike  
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31 Keywords: "recovery"; "hearing voices"; "schizophrenia"; "qualitative"; "psychotic  
32 experiences"  
33

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3 35 **Abstract**

4 36

5 37 *Objectives*

6  
7  
8 38 Little research has looked at how people who do not use mental health services  
9  
10 39 experience psychosis. Thus, the present study aimed to explore the experiences and  
11  
12 40 views of people with psychosis who have neither sought nor received support from  
13  
14 41 mental health services for at least five years.  
15  
16

17  
18 42 *Design*

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20  
21 43 A narrative interview study. Thematic analysis was used to analyse the data.  
22  
23

24 44 *Setting*

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27 45 United Kingdom  
28  
29

30 46 *Participants*

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33 47 Twenty-eight participants with self-defined psychotic experiences were asked to  
34  
35 48 provide a free narrative about their experiences.  
36  
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38

39 49 *Results*

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41  
42 50 Five themes were identified: 1) Perceiving psychosis as positive 2) Making sense of  
43  
44 51 psychotic experiences as a more active psychological process to find explanations and  
45  
46 52 meaning; 3) Finding sources of strength, mainly in relationships and the environment,  
47  
48 53 but outside of services; 4) Negative past experiences of mental health services, leading  
49  
50 54 to disengagement; and 5) Positive past experiences with individual clinicians, as an  
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52 55 appreciation of individuals despite negative views of services as a whole.  
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3 57 *Conclusions*  
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6 58 Perceiving psychosis as something positive, a process of making sense of psychotic  
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8 59 experiences and the ability to find external sources of strength all underpin – in addition  
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10  
11 60 to negative experiences with services - a choice to live with psychosis outside of  
12  
13 61 services. Future research may explore to what extent these perceptions, psychological  
14  
15 62 processes and abilities can be facilitated and strengthened, in order to support those  
16  
17 63 people with psychosis who do not seek treatment and possibly also some of those who  
18  
19 64 are in treatment.  
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26 66 *Strengths and limitations of this study*  
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28

- 29 67 - To our knowledge, this study is one of the first to explore the experiences of  
30  
31 68 people with psychosis outside of services who are hard to reach and commonly  
32  
33 69 not included in research studies.  
34  
35  
36 70 - A free narrative approach emphasised the perspective of the interviewees and  
37  
38 71 allowed for rich material to be analysed.  
39  
40  
41 72 - The participants included in this study were recruited from a wide-range of  
42  
43 73 organisations and geographical areas within the United Kingdom, thus enabling a  
44  
45 74 maximum variation within the target population.  
46  
47  
48 75 - The sample was heterogeneous in terms of biographies and living situations, but  
49  
50 76 it was a convenience sample and exclusively from England.  
51  
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53 77 - The study did not entail formal diagnostic assessments.  
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## 1. Introduction

81  
82 Research has shown that a considerable number of people with psychosis do not present  
83 to mental health services.[1] According to one review, 7% of the general population are  
84 likely to have psychotic experiences in their lifetime.[2] Other reviews estimate voice-  
85 hearing prevalence at 13%[3] and experience of paranoia in up to 30% of the general  
86 population.[4] Since these rates are much higher than the numbers of patients with  
87 psychosis in health services[5], many people with such experiences are likely to live with  
88 and manage their experiences without conventional treatment or other support from  
89 mental health services.

90  
91 There is a debate as to whether the psychosis-like experiences in the general population  
92 are qualitatively distinct from those in clinical populations.[6,7] Peters and colleagues  
93 (2016)[8] found that both clinical and non-clinical groups with psychotic experiences  
94 experienced positive symptoms. Interestingly, the non-clinical group had lower levels of  
95 paranoia, delusions, cognitive difficulties and negative symptoms, but more somatic or  
96 tactile hallucinations.

97  
98 Previous literature exploring the views of people with psychotic-like experiences who do  
99 not seek support from mental health services is scarce. To our knowledge, one prior  
100 study conducted by Boumans and colleagues (2017) [9] documented two key factors in  
101 maintaining wellbeing without having to access mental health services: personalised self-  
102 care and adoption of interpretive frameworks (in order to fully make sense of psychotic  
103 experiences).

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3 104 Studying the experiences of people with psychosis outside of services can be  
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5 105 challenging, as many people in such situations may avoid not only contact with health  
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8 106 services, but also participation in research studies. However, such research may:  
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10 107 identify different strategies for living with psychosis than those found in clinical  
11  
12 108 samples; point towards forms of support that are appropriate for people with psychosis  
13  
14 109 who do not seek treatment; and provide evidence on attitudes, skills and resources that  
15  
16 110 can promote recovery also in other groups.[10] Against this background, the current  
17  
18 111 study aimed to explore the experiences and views of people with psychotic experiences  
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20 112 who have not received any treatment or other support from mental health services for  
21  
22 113 the past five years.  
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## 115 **2. Methods**

### 116 **2.1 Study Design**

117 We conducted qualitative semi-structured narrative interviews. The narrative  
118 methodological approach was chosen as it enables a flexible collection of rich material  
119 whilst simultaneously placing emphasis on the perspective of the interviewees. [11] A  
120 Lived Experience Advisory Panel advised on the content and conduct of the interview,  
121 including the phrasing of questions and the terminology used in the interviews.  
122 As per the ethics application, the study had a pre-defined sample size of up to 30  
123 participants. It was agreed that participant recruitment would be terminated after data  
124 saturation was reached.  
125  
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127

## 128 2.2 Participants and Recruitment Activities

129

130 Participants met the following inclusion criteria: having had self-defined experiences of  
131 what could be termed psychosis (with examples given of hearing voices or seeing or  
132 believing things that others do not), not having accessed mental health services for the  
133 previous five years although they may have had accessed them earlier (i.e. secondary or  
134 tertiary mental health services in the categorisation of the National Health Service in the  
135 United Kingdom, i.e. services providing treatment through fully qualified mental health  
136 professionals), over 17 years of age, and able to give informed consent.

137

138 Recruitment activities were structured and iteratively refined to seek a maximum  
139 variation sample of psychosis experiences. [12] To achieve a maximum variation sample  
140 of psychosis experiences, participants from a wide range of organisations and  
141 geographical areas (in and outside of London) were recruited. The recruitment of  
142 participants took place through: primary care (general practitioner practices) services  
143 in London, online support groups or networks (e.g. spiritual or critical psychiatry  
144 networks), groups affiliated to the Hearing Voices Network, and charity and non-  
145 governmental organisations. It is important to highlight that the organisations included  
146 in the current study do not provide specialist mental health treatment or support.  
147 Although the recruitment method varied slightly depending on the site being recruited  
148 from, in most instances the recruitment was facilitated by presentations and attendance  
149 at a variety of groups, advertising online or sending invitation letters to potential  
150 participants.

151

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3 152 Researchers explained the details of the study on the phone with potential participants,  
4  
5 153 and encouraged them to ask any questions or raise concerns. This was followed by a  
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7  
8 154 meeting in person, in which individuals could make their final decision as to whether to  
9  
10 155 take part in the research interview. All participants received a participant information  
11  
12 156 sheet and were given a sufficient amount of time to consider whether to participate in  
13  
14  
15 157 the study. As part of the recruitment process, all of the eligibility criteria were discussed  
16  
17 158 with each participant to verify that they were being met. There was no prior  
18  
19 159 relationship between the researchers conducting the interviews and the study  
20  
21  
22 160 participants.  
23  
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25 161

### 26 162 **2.3 Procedure**

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29 163 Twenty-eight semi-structured interviews were conducted by three researchers (RM, ZJ  
30  
31 164 and JLB) over a 15-month period, with most interviews (n=25) carried out by RM. Most  
32  
33 165 interviews were conducted in London, with some in other parts of England. Each  
34  
35 166 participant took part in a 40-120 minute interview conducted in health services or  
36  
37 167 community venues. On the day of the interview, researchers provided the potential  
38  
39 168 participants with an in-depth explanation of the study procedures and aims, ensuring  
40  
41 169 their full understanding and ability to provide informed consent. During the interviews,  
42  
43 170 the researchers asked open-ended questions designed to elicit a narrative, [13] with  
44  
45 171 minimal or no interruption from the researcher in order to facilitate fluent sharing of  
46  
47 172 experiences.[14] Specifically, participants were asked to share their recovery story,  
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49 173 followed by some questions focusing on participants' experiences of sharing their  
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51 174 recovery story with others. All participants were reimbursed for their participation.  
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## 177 **2.4 Analysis**

178 Interviews were audio-recorded, transcribed verbatim, anonymised, and were then  
179 transferred to NVivo 11 for data management and analysis. After the researchers  
180 familiarised themselves with the content of the data, an initial inductive thematic  
181 analysis was conducted to identify key themes across the interviews, based on an  
182 approach outlined by Braun and Clarke (2006).[15] Preliminary codes were  
183 established from this analysis in relation to the research question, and refined through a  
184 continuous discussion in the wider research team, from backgrounds in clinical and  
185 academic psychiatry and clinical and academic psychology. Transcripts were then  
186 analysed in more detail by two members of the research team, with 20% being double  
187 coded and checked for consistency by two independent researchers. Discrepancies were  
188 discussed until resolved. Coding consisted of identification and allocation of text  
189 relating to the preliminary coding framework, allowing comparison of themes occurring  
190 within and across sources. Once all transcripts were coded, the lead author synthesised  
191 the coding into themes with the two analysts. Regular discussions were held between all  
192 analysts to adapt and develop the themes, which underwent several iterations from its  
193 original form to the final version. The researchers maintained reflexivity by consistently  
194 having discussions within the team and with the wider research group to gain a more  
195 varied perspective. Reflexive field notes were also utilised which focused on the  
196 researcher's role as an interviewer, including their feelings, possible biases and  
197 immediate context prior to the interview in order to further ensure reflexivity.

198

199

200

## 201 **2.5 Ethics**

202 This research was undertaken as part of the NIHR Narrative Experiences Online (NEON)  
203 study (ISRCTN11152837, information at <http://www.researchintorecovery.com/neon>)  
204 between March 2018 and August 2019. Ethical Committee approval was obtained in  
205 advance (Nottingham 2 REC 17/EM/0401). All participants provided written informed  
206 consent.

207

## 208 **Patient and Public Involvement**

209 A Lived Experience Advisory Panel advised on the content and conduct of the interview.

210

211

## 212 **3. Results**

### 213 **3.1 Sample**

214 Twenty-eight people with self-defined psychotic experiences were interviewed between  
215 February 2018 and May 2019. The duration of the interviews ranged from 40 to 120  
216 minutes. Eleven participants were recruited via primary care practices and 17 through  
217 alternative networks and advertising. Sixteen were female, and 11 male (1 preferred not  
218 to say). Four participants reported being in the age group of 25-34 years; 6 in the group  
219 of 25-44 years; 9 in the group of 45-54 years; 4 in the group of 55-64 years; and 2 being  
220 more than 64 years of age (1 preferred not to say). Eighteen self-declared ethnicity as  
221 White, 2 as Asian, and 5 as Black (3 preferred not to say).

222

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227

## 228 3.2 Themes

229 Five distinct themes were identified.

230

### 231 3.2.1 Perceiving psychosis as positive

232 A large proportion of participants perceived their experience of psychosis as positive

233 overall.

234 *"I think I have something extraordinary. And people with extraordinary things find it hard*

235 *in society, and probably I don't find it hard'* (A01)

236 For some, this related to seeing such experiences, e.g. their hallucinations, as a positive

237 coping mechanism to deal with difficult life events, even if the hallucinations themselves

238 could be difficult:

239 *"...my brain was trying to process all the things happening around me, and tried to*

240 *externalise it in some form that I could perhaps deal with a bit better..."* (A27)

241 Others found their experiences educational or empowering, and were able to learn or

242 gain new and positive perspectives from them:

243 *"I kind of tried to get rid of all the negativity and then ended up getting like a higher kind of*

244 *version of myself so I felt really empowered and really kind of connected to the universe"*

245 (A02)

246 *"I feel that in that space I get some real truths"* (A010)

247 For some, their psychosis had become a positive part of their identity, an essential part of

248 how they saw themselves in the world, providing a resource that they could contribute:

249 *"I have taken the only course open to me to cope with symptoms, that is to treat seeing*

250 *things which are not there, or hearing what nobody else does, as attributes which in truth*

1  
2  
3 251 *are a part of who I am and harnessing them as the strengths they really are, and the gifts*  
4  
5  
6 252 *which I have to give the world.” (A19)*

7  
8 253 *“...in a way I see it as a positive, they don't have to be negative, you can actually accept*  
9  
10 254 *who you are and.. you make the best of it really” (A020)*

11  
12  
13 255

### 16 256 3.2.2 *Making sense of psychotic experiences*

17  
18 257 When people managed to make sense of their psychotic experiences, this often also  
19  
20 258 implied a positive view of the experiences. It was, however, not just a positive  
21  
22 259 perspective of what happened. It often involved a more active psychological process of  
23  
24 260 developing a meaningful explanation. Indeed, the process of making sense of the  
25  
26 261 psychotic experiences was also often linked to the biographical context of the individual.  
27  
28 262 An explanation for why they had experienced psychosis was important, and these  
29  
30 263 explanations themselves became a significant part of their narratives.

31  
32 264 *“I have since learnt that actually there is meaning to things and actually I am somebody*  
33  
34 265 *that..does seem to have a perception or radar that not everybody seems to have..in one*  
35  
36 266 *way the psychosis was awful, but in another way it exposed this horrible past that was*  
37  
38 267 *unknown, unexplored, unexpressed” (A07)*

39  
40  
41 268 Many linked their experiences with negative life events, such as abuse in childhood or  
42  
43 269 difficult upbringing:

44  
45 270 *“...I've been a voice hearer and someone who hallucinates since I was little. ...the reason for*  
46  
47 271 *that in my particular case is because I am a survivor of incest.” (A05)*

48  
49 272 *“...I come from a fairly dysfunctional family..It did actually take me years and years to put*  
50  
51 273 *together the idea.... that the mental health problems sort of arose as..a means for my brain*  
52  
53 274 *to externalise what was going on inside.. sometimes they (hallucinations) were more*

1  
2  
3 275 *supportive than the people around me were.... maybe my brain created an enviroment for*  
4  
5 276 *me..to be in..I understood better...I had control of” (A027)*  
6  
7

8  
9 277 These negative experiences could be from a period before individuals were able to form  
10  
11 278 memories, so that finding out about their past could make sense of their experiences:

12  
13 279 *“And that's when I found out that we'd been separated when I was a very, very young baby...*  
14  
15 280 *...so you know and my soothing- self-soothing system probably wasn't that well developed,*  
16  
17 281 *so that helped me to understand” (A11)*  
18  
19

20 282 Other negative experiences were from later in life:

21  
22 283 *“...my mental health challenges were triggered by having radical surgery. I mean it is - it is*  
23  
24 284 *important to say this, so, before (the surgery) I hadn't experienced (mental health*  
25  
26 285 *challenges)...” (A16)*  
27  
28

29 286 Some attributed their experiences to spiritual reasons, finding them empowering and  
30  
31 287 meaningful:

32  
33 288 *“This story is in my ancestry, that's my theory of what happened, I don't have any other*  
34  
35 289 *explanation and I felt that there was- I felt that's what happened to me” (A10)*  
36  
37

38  
39 290 These explanations were sometimes linked to religious beliefs:

40  
41 291 *“...as a Christian I don't see anything that ever happens to anybody as being a result of*  
42  
43 292 *random chance anymore, I think it was important to my journey” (A22)*  
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3 299 3.2.3 Finding sources of strength  
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6 300 A third theme was the sources of strength that participants found around them, in  
7  
8 301 relationships and in their natural environment, but outside of mental health services.

9 302 These included both receiving and giving social support, and the validation and feelings  
10  
11 303 of connection provided by others, particularly those with similar experiences:

12  
13 304 *"...it was amazing, we all kind of met up and we had all been through similar things, and it*  
14  
15 305 *was incredible to just hear everyone speak and be open"* (A02)

16  
17 306 The significance of social support was also expressed in terms of the importance of close  
18  
19 307 personal relationships:

20  
21 308 *"Well I think my partners have been too important in my life. So the first time when I got*  
22  
23 309 *my diagnosis I was with my boyfriend... at that time he was very, very, very supportive and*  
24  
25 310 *so was his family."* (A09)

26  
27 311 Some people spoke about the importance of taking ownership of their narrative for their  
28  
29 312 recovery, creating a coherent sequence of events, often through counselling or  
30  
31 313 alternative therapy work:

32  
33 314 *"...part of the reason I find narrative therapy actually so interesting as an approach is that*  
34  
35 315 *part of the recovery process has been assembling the story. And understanding it as a story."*  
36  
37 316 (A06)

38  
39 317 Others found the process of creating a written narrative cathartic:

40  
41 318 *"...I wrote my autobiography so that was a big part of my healing process, it was- It was a*  
42  
43 319 *catharsis I needed to look back and understand my journey... that... was a huge part of my*  
44  
45 320 *healing process."* (A11)

46  
47 321 For some, opposing the dominant illness model of psychosis and using spiritual or other  
48  
49 322 alternative frameworks to make sense of their experiences was essential to being well:

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3 323 *"...going into the different reality... and taking it seriously rather than dismissing it as*  
4  
5 324 *illness was my recovery, that was what helped me to recover, I think."* (A10)

7  
8 325 Many people spoke about the importance of self-care in managing their mental health,  
9  
10 326 and finding ways to improve their wellbeing on a daily basis. For example, people found  
11  
12 327 exercise and healthy eating to be helpful:

14  
15 328 *"I started to exercise, and I'd started to clean up my food, and I started to do a bit of*  
16  
17 329 *meditation.... And I said, oh, wow, this is how you get better then."* (A16)

19  
20 330 Other forms of self-care mentioned were making time and space for oneself, and  
21  
22 331 spending time in nature:

24  
25 332 *"I love the sea, every time I feel like anxious and nervous I just look at the sea and it is just,*  
26  
27 333 *like, beautiful."* (A02)

29  
30 334 Another helpful factor people spoke about was finding purpose in daily life, and  
31  
32 335 productive ways to use their time. These could entail creative outlets such as music and  
33  
34 336 art forms:

36  
37 337 *"...it's recovery through my artwork every day... - I think the art has given me great kind of-*  
38  
39 338 *great kind of structure..."* (A01)

41  
42 339 For others, purpose was achieved by engaging in or returning to higher education or  
43  
44 340 seeking to educate themselves:

45  
46 341 *"...it was important to me sort of coming back to schooling, that was... unfinished business*  
47  
48 342 *because I could never go..."* (A04)

49  
50 343 Others found purpose in voluntary or paid employment:

52  
53 344 *"...the job that I do is what keeps me out of hospital, I know it yeah, and it has done for all*  
54  
55 345 *that time because I haven't been hospitalised..."* (A12)

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3 347 3.2.4 *Negative past experiences of mental health services*  
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6 348 Some participants had previously engaged with services, and several of them reported  
7  
8 349 negative experiences of treatments and interactions with staff, which contributed to their  
9  
10  
11 350 decision to disengage from health services. These could relate to unwanted medication  
12  
13 351 side effects:

14  
15  
16 352 *"The medication didn't help at all, actually it numbed me so much that I had no point any*  
17  
18 353 *more"* (A04)

19  
20  
21 354 But also to coercive and forceful treatment by staff:

22  
23  
24 355 *"I remember they were dragging me up the ward... to the seclusion room, where they*  
25  
26 356 *monitored me...they were very, very forceful and all I said was I just need your help and.....it*  
27  
28 357 *wasn't really dealt with, no-one answered back, that was the process."* (A021)

29  
30  
31 358 *"The regime was punitive...if you...stepped out of line... the notion was you would receive*  
32  
33 359 *more intensive care which of course was nonsense, it was a form of punishment."* (A020)

34  
35  
36 360 And indeed abuse, as reported by two participants:

37  
38 361 *"Unfortunately I was raped in hospital and it made it - made it very uncomfortable to be*  
39  
40 362 *there so I left really quickly."* (A03)

41  
42  
43 363 *"...when I was sectioned um in the local mental health hospital I was raped, probably by*  
44  
45 364 *staff, which added to my trauma..."* (A05)

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3 370 3.2.5 Positive past experiences with individual clinicians  
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6 371 However, past experiences with services were mixed. Those people who reported  
7  
8 372 positive experiences often referred to the importance of helpful relationships with  
9  
10 373 individual clinicians, rather than a team or a whole service, so that these positive  
11  
12 374 interactions did not provide a motivation to re-engage with the service. The individual  
13  
14 375 clinicians made them feel “heard”, and were able to see them as a whole person as  
15  
16 376 opposed to the sum of their symptoms:  
17  
18  
19

20 377 *“When I said to him (psychiatrist), he said ‘tell me about yourself’ I said ‘there it is, read*  
21  
22 378 *this’ he pushed my file away and said ‘that’s a piece of paper- it tells me nothing about you’*  
23  
24 379 *and then we connected, we clicked” (A17)*  
25  
26

27 380 Others spoke about clinicians who did not discount the validity of their experiences and  
28  
29 381 their potential meaning, respecting their interpretations of experiences:  
30  
31

32 382 *“...I had a couple of sessions with a psychiatrist... ...and I actually said to him ‘do you think*  
33  
34 383 *it’s possible to see, like have an episode like a psychotic episode and in that episode literally*  
35  
36 384 *see the things that you’re going to experience in your life all in that episode and then*  
37  
38 385 *everything actually begin very, very slowly’ and he said ‘it’s possible, you know’.” (A08)*  
39  
40

41 386 Even participants with negative views of services as a whole, tended to distinguish  
42  
43 387 between individual clinicians. The participant who criticised a punitive regime in the  
44  
45 388 previous theme also remarked:  
46  
47  
48

49 389 *“I thought the psychiatrist was very pleasant, we had some interesting chats...(after*  
50  
51 390 *leaving)..I felt the loss of the attention of the psychiatrists..” (A020)*  
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#### 393 4. Discussion

394

395 We explored the experiences and views of people living with psychotic experiences, who  
396 have neither sought nor received any support from mental health services in the last five  
397 years. The focus was on understanding how people describe their views and experiences  
398 when not receiving treatment or any other type of help from mental health professionals.  
399 Five themes were identified in the narratives. Three themes reflect views and abilities  
400 that may be essential for the participants' choice for not contacting services. They include  
401 a positive perception of psychotic experiences even if they are seen as unusual, an active  
402 and – at least in parts – successful search for sense and meaning, and a link with the  
403 external world in form of finding strength in personal and natural sources around them.  
404 Two further themes address the past experiences with services, which were often  
405 negative but also involved helpful relationships with individual clinicians.

#### 406 *Strengths and limitations*

407 Whilst numerous studies have investigated how patients with diagnosed psychotic  
408 disorders experience and are satisfied or dissatisfied with the treatment they have been  
409 receiving in mental health services, this is one of the first studies to explore the  
410 narratives of a hard-to-reach population of people with experiences of psychosis who are  
411 not in contact with mental health services. The methodological approach of encouraging  
412 people to tell their story in a free narrative emphasised the perspective of the  
413 interviewees and allowed for rich material to be analysed. We recruited from different  
414 groups, and reached saturation for generating the main themes.

415 The study also has several limitations. Firstly, we recruited a convenience sample. Given  
416 that there may be very different groups of people with the experience of psychosis who

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3 417 do not use mental health services, other samples may have yielded a different picture.  
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5 418 Secondly, although the sample was selective, it was still heterogeneous in terms of  
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8 419 biographies and living situations. However, it was overall too small to analyse differences  
9  
10 420 between subgroups. Thirdly, the approach of a free narrative limited the option to focus  
11  
12 421 on specific aspects in more depth and detail. And finally, neither did the interviewers  
13  
14 422 conduct a formal diagnostic assessment nor did they check the diagnostic assessment of  
15  
16 423 possible treatment episodes in the past. Thus, one may question to what extent  
17  
18 424 experiences of the interviewees would be classified as psychosis if such formal  
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20 425 assessments had been made.  
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#### 25 426 *Summary of the results and comparison against the literature*

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28 427 A previous study investigating the experiences of people with psychotic symptoms not  
29  
30 428 accessing mental health services [9] found themes relating to self-care and the  
31  
32 429 importance of underlying explanatory frameworks. Similarly, two themes in this study  
33  
34 430 centre on the importance of individuals' positive perceptions of their experiences and  
35  
36 431 finding a meaningful explanation. Perceiving psychotic experiences as meaningful and  
37  
38 432 related to their life situation has been shown to be beneficial for people's prospects of  
39  
40 433 recovery. [16]<sup>2</sup>  
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47 435 The findings suggest that it is important that people's explanations are aligned with and  
48  
49 436 accepted by others, as well as contain personal meaning. An aspect of helpful social  
50  
51 437 support was sharing a joint explanatory model for their experiences, and receiving  
52  
53 438 validation of these beliefs. In addition, we found that individual relationships with  
54  
55 439 clinicians could be particularly helpful when individuals felt that they were listened to,  
56  
57 440 and their explanations were taken seriously. This is in line with previous research  
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3 441 showing that sharing the same explanatory model for psychosis is associated with  
4  
5 442 improved treatment satisfaction and therapeutic relationship in outpatients diagnosed  
6  
7 443 with schizophrenia[17] and more generally with a large body of evidence showing the  
8  
9 444 importance of the direct communication between patients and individual clinicians.[18]□  
10  
11 445 The importance of establishing a positive patient-clinician relationship through  
12  
13 446 appropriate communication is underlined by the fact that many participants still  
14  
15 447 expressed their appreciation for individual clinicians, although these relationships had  
16  
17 448 ceased at least five years before and all participants had decided not seek help from  
18  
19 449 mental health services in general anymore.  
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450

26 451 Many of the participants believed that specific traumatic experiences had played a causal  
27  
28 452 role in the development of psychotic experiences. Previous narrative reviews and meta-  
29  
30 453 analyses have suggested a link between traumatic experiences and psychosis [19–21],  
31  
32 454 which may be influenced by lower psychosocial functioning and greater social  
33  
34 455 adversity.[8]□  
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456

40 457 Having social connections was considered helpful not only in relation to the validation of  
41  
42 458 explanatory models, but also for daily support and wellbeing, which is consistent with  
43  
44 459 research showing the important role of social networks for recovery. [22,23] In addition,  
45  
46 460 people spoke about the importance of being engaged in occupations, religious groups and  
47  
48 461 creative activities. Such activities may provide purpose and structure. [24] Structure and  
49  
50 462 using various forms of self-care to stay well have been found to be associated with larger  
51  
52 463 social networks. [25]□  
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3 465 That people who prefer not to be in contact with services report a range of negative past  
4  
5 466 experiences with services is not surprising. Indeed, the fact that negative experiences can  
6  
7 467 lead to disengagement has been shown before [26] and may be seen as obvious. Some  
8  
9 468 people reported extremely stressful events such as being raped which can easily be  
10  
11 469 understood as a reason to avoid any contact with services from then onwards. Overall,  
12  
13 470 however, the negative reports about experiences with services were not more  
14  
15 471 pronounced than in some studies with people who are still - or again - in  
16  
17 472 treatment.[26,27] Explanatory models for their experiences that are not shared, the  
18  
19 473 feeling of not being listened to or treated with respect, and further stressful events  
20  
21 474 during treatment, particularly on wards, are frequently found in accounts of patients who  
22  
23 475 are in care of mental health services too.[28,29] Moreover, people in this study  
24  
25 476 repeatedly described very positive experiences with individual clinicians although this  
26  
27 477 did not generalise to positive views of the services as a whole. Thus, one may speculate  
28  
29 478 as to whether the negative experiences reported in this study are rather common and  
30  
31 479 possibly less important than the positive views and resources in relation to the decision  
32  
33 480 not to seek treatment as well as the ability to manage psychotic experiences outside  
34  
35 481 services. Seeing psychotic experiences – for various reasons - as something positive,  
36  
37 482 making sense of the experiences and finding external sources of strength might be more  
38  
39 483 specific for this group of people than the critical views of health services.  
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3 489 *Conclusions*  
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6 490  
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8 491 Given a lack of previous literature, the current study sought to explore the experiences  
9  
10 492 and views of people with psychotic experiences who have neither sought nor received  
11  
12 493 support from mental health services for at least five years by employing a free narrative  
13  
14 494 interview methodology.  
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16

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18

19 496 However, it remains an open question as to whether any and, if so, how many of the  
20  
21  
22 497 interviewees might actually have benefitted from whatever support mental health  
23  
24 498 services in the given area can provide. Services that accommodate and respect a range  
25  
26 499 of explanatory models and have clinicians with good communication skills who treat  
27  
28 500 patients with interest and respect should be more likely to maintain helpful  
29  
30 501 relationships even with people who have different explanations for their experiences.  
31  
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33 502 This might even outweigh some negative treatment experiences that many patients  
34  
35 503 might have at some stage of their long-term pathways.  
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40 505 A challenge for future research is to explore whether it is possible to facilitate and  
41  
42 506 strengthen the positive perceptions, psychological processes and abilities to find strength  
43  
44 507 in engaging with external sources, that were identified in this study. Such research might  
45  
46 508 lead to better support for people with psychosis who do not seek treatment. It might also  
47  
48 509 benefit the further development of approaches for people with psychosis who are in  
49  
50 510 treatment, as it could help their recovery although in some patients it might also  
51  
52 511 undermine the motivation to stay in treatment.  
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4  
5

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9 517

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11  
12 518 **A competing interests statement**  
13

14 519 The authors have no conflicts of interest to disclose.  
15 520

16  
17  
18 521 **Contribution**  
19

20  
21 522 SP designed the study and led the analysis, MS was in charge of the overall research  
22 523 programme and SE co-ordinated data collection across sites. The interviews were  
23 524 conducted by RM, ZJ whilst all the transcripts were read by RM, ZJ, AE and SP. The  
24 525 analysis of the data and discussions regarding the codes/themes were undertaken by  
25 526 RM, ZJ, AE and SP. RM wrote the first draft of the manuscript. All of the co-authors have  
26 527 contributed towards revisions of the manuscript and have approved the final version of  
27 528 it.  
28  
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32 531 **Data Availability Statement**  
33

34 532

35 533 No additional data are available  
36 534

37 535

38 536

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40

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45 542

46 543

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48

49 545

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52 548 between March 2018 and August 2019. Ethical Committee approval was obtained in  
53 549 advance (Nottingham 2 REC 17/EM/0401). All participants provided written informed  
54 550 consent.  
55 551

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**SRQR**

**Item 1 – Title - Yes – Page 1; Lines 1-2**

**Item 2 – Abstract - Yes – Page 2-3; Lines 35-64**

**Item 3 – Problem Formulation -Yes - Page 4 to 5; Lines 83-113**

**Item 4 – Purpose or research question- Yes - Page 5; Lines 110-113**

**Item 5 - Qualitative Approach - Yes – Page 5; Lines 117-119**

**Item 6 – Researcher characteristics and reflexivity - Yes – Page 8; Lines 184; 192-196.**

**Item 7 – Setting/Site; Yes – Page 6; Lines 140-149**

**Item 8 – Sampling Strategy - Yes – Page 5-6; Lines 137-150.**

**Item 9 – Ethics - Yes – Page 9; Lines 200-205.**

**Item 10 – Data Collection Methods - Yes – Page 5 and 7; 168-173; 117-119.**

**Item 11 – Data Collection Instruments and Technologies- Yes – Page 5 and 7; 168-173; 117-119.**

**Item 12 – Units of Study –Page 6; Lines 130-135.**

**Item 13 – Data processing - Yes – Page 8; Lines 177-178**

**Item 14 – Data Analysis - Yes – Page 8; Lines 176-196.**

**Item 15 – Techniques used to enhance trustworthiness - Yes – Page 8; Lines 184-186.**

**Item 16 - Synthesis and interpretation - Yes – Pages 9-16; Lines 207-388.**

**Item 17 – Links to empirical data - Yes – Pages 10-16; Lines 226 – 388.**

**Item 18 – Integration with prior work, implications, transferability, and contribution(s) to the field  
Yes – Page 17 to 21 Lines 391-509.**

**Item 19 – Limitations - Yes – Pages 17-18; Lines 404-423.**

**Item 20 Conflicts of Interest -Yes – Page 22; Lines 516-517.**

**Item 21 Funding – Yes – Page 22; Lines 511-514.**