

# Psychosis

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# How do people talk decades later about their crisis that we call psychosis? A qualitative study of the personal meaning-making process

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## ABSTRACT

*Psychosis* refers to a severe mental state that often significantly affects the individual's life course. However, it remains unclear how people with the lived experiences themselves view these phenomena, as part of their life story. In order to evaluate this personal meaning-making process, we conducted in-depth life-story interviews with 20 people who had been diagnosed with non-affective psychosis 10 to 23 years previously in one catchment area. 35% of them were still receiving mental health treatment, and 55% of them were diagnosed with schizophrenia. Only a minority named their experiences as psychosis. On the basis of narrative analysis, two types of stories appeared to encompass how mental health crises and/or related experiences were presented as part of the life story: (i) crisis as a disruptor of the normative course of life ( $N=9$ ), and (ii) crisis as an expected reaction to life adversities ( $N=7$ ). In the majority of the stories, the mental health crisis was associated with cumulative life adversities in a central life area. Correspondingly, most of the factors that brought relief were narrated as inseparable from social and other real-life environments. We discuss the need for more person-centred and collaborative models of research and treatment.

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## Introduction

The term *psychosis* is often used to categorize a wide range of mental states characterized by difficulties in distinguishing what is real from what is not. From the clinical and the scientific perspective, challenges derive from the multifaceted nature of the phenomena, and from the variety of conceptions that can be applied (Borchers, 2014). Thus, for many people, the term is associated with significant suffering, whereas for others the hearing of voices, or other experiences categorized as belonging to psychosis, can be meaningful and valuable. As Putnam (2018, p.2) has noted: "many co-constructed spaces from which to see and respond to psychosis – culturally, relationally, psychologically, and neurologically – may be multiple facets of the same reality."

The dominant clinical language can sometimes disregard people's subjective experiences (Borchers, 2014), making it more difficult for clinicians to understand the phenomena they

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encounter, and to interact with people who have experienced them. Especially the service user/survivor-led research has overhaul the conceptual basis of psychiatry by underlying both the importance of collectively produced knowledge and the challenges relating to the singular conceptualisations (e.g. Rose, 2017). In recognition of this, there has been a growth in research on individuals' experiences of psychosis (Boydell, Stasiulis, Volpe, & Gladstone, 2010; McCarthy-Jones, Marriot, Knowles, Rowse, & Thompson, 2013). Since humans make sense of their own experiences via stories (McAdams, 2001), one possibility to increase understanding of the matter is to research the life stories of people with the lived experiences.

In this study, in-depth life-story interviews were conducted with people who, about 20 years ago, had for the first time received mental health treatment for a severe mental crisis. The primary aim was to explore (i) how people themselves give meanings to experiences which, in the clinical context, are often interpreted as psychosis, and (ii) how these experiences are included in life stories.

## Methods

### *Theoretical approach*

We applied a phenomenologically based methodology, with an emphasis on the subjective and interrelated nature of experiences. The design nevertheless differed from traditional phenomenological research, as we did not aim to arrive at the "core essences" of the experiences. In line with Georgaca's (2013) presentation on research trends in qualitative studies of psychosis, our study can be viewed as a qualitative empirical study, within which narrative and dialogical approaches were also applied to interpret the material.

The narration was regarded as a psychological meaning-making process, capable of providing unity to human lives. By constantly reconstructing the past, present, and future, individuals can be viewed as maintaining their identities via life stories (McAdams, 2001). As experiences interpreted as psychosis have frequently been associated with a disruption in the sense of self, and thus with a loosened ability to maintain coherent inner dialogues (Lysaker & Lysaker, 2002; Roe & Davidson, 2005), narrative inquiry could provide a useful framework for research on these phenomenon. For example, Lysaker (2002) has argued that alteration of the dialogical structure of the self is the primary feature of psychosis since it has dramatic consequences to ability to interact with others and act in the world. Moreover, research on narratives and psychosis have been consistent with the idea that people make sense of their problems via life stories, and they have shown the multifaceted ways on how people narrate and understand their experiences (Roe, Hasson-Ohayon, Kravetz, Yanos, & Lysaker, 2008).

In socially oriented approaches it has been recognized that the culturally dominant stories, preferred usually by significant others, might marginalize the alternative stories that are providing other ways of understanding the experiences, eventually leading to the diminished sense of agency (Holma & Aaltonen, 1997). In line with this, many of the phenomena categorized as psychotic can be seen as a person's attempts to make sense of difficult experiences that do not have a language to express them, other than, for example, hallucinations and delusions (Seikkula, Alakare, & Aaltonen, 2001). According to this dialogical perspective, psychosis is emerging in relationships that do not guarantee adequate responses. Psychosis cannot thus be viewed as a categorical or pathological phenomena, but instead, an understandable way to respond in extreme stress, similarly associated to embodied and relational mind as any other affective arousals (Seikkula, *in press*).

From a more social constructionist point of view, the narratives about psychosis are always co-created within social systems (France & Uhlin, 2006). Even though we share this view and thus attempted to avoid conventional medical language with pre-determined assumptions concerning, for example, the aetiology of phenomena, in the present study more moderate epistemological

position was adopted: it was recognized that there is also world independent of our knowledge and language, even if our knowledge from it remains incomplete and subjective.

### **Participants and recruitment**

The participants for in-depth interviews were recruited from the *Western Lapland* research cohort (N = 108). This included all persons treated for first-episode psychosis in the area of Western Lapland health-care districts, Finland, within three inclusion periods (Seikkula, Alakare, & Aaltonen, 2011). At onset, all persons within the cohort were treatment-naïve and were diagnosed with non-affective psychosis (ICD-10 codes: F20–F29). Individual follow-up extended from 10 to 23 years. All the persons in the cohort were initially treated in accordance with the principles of the Open Dialogue approach (OD) (Seikkula et al., 2011), in which a primary goal is to collaboratively support the person and their social networks in the co-creation of a shared understanding for the difficult experiences they are undergoing. More detailed descriptions concerning the catchment area, research cohort, diagnostic procedures, and the treatment, are presented elsewhere (Bergström et al., 2018; Seikkula et al., 2011). The research plan was reviewed and approved by the North Ostrobothnia hospital districts ethical committee.

The invitation letters were sent to all candidates (N = 77) who were still living in the Western Lapland area or up to approximately 500 km from it. In addition to the letters sent out, the local health-care staff in Western Lapland area were asked to recruit verbally persons from this group who were still receiving treatment (N = 18). In the letter, people were invited to come and talk about their experiences of treatment and to give more comprehensive descriptions of their lives, with a view to improving understanding how mental health issues should be approached. In order not to arouse negative emotions, the letter avoided the use of diagnostic terms, or other references to medical conditions, making only a general reference to an earlier need for mental health services. From the total of 77 invited people, 21 (27%) expressed their willingness to participate, 14 (18%) declined, and the remainder (55%) did not react. One person subsequently retracted participation.

All participants (N = 20) completed informed consent forms, in which they gave permission to use information obtained via interviews, and to combine this with register information obtained from local medical records. Due to the sensitive nature of the topic, all the participants were given the opportunity to continue the discussions afterwards with experienced clinicians. One participant indicated that the interview aroused unpleasant memories, while the remaining interviewees viewed the interview as neutral or positive experience.

### **Interviews**

At the start of the interview, all participants were encouraged to relate their life stories as precisely as they could. To address the more specific aims of this study, all the participants were later asked to describe more comprehensively (i) their own personal characteristics, (ii) significant child- and adulthood life-events, (iii) views as to what (the term used by a participant) had led up to the treatment, (iv) what was it like for them, (v) how they survived, and (vi) how it affected their later life course. Even though the interviews focused on the participants' own experiences, and on what was relevant for them, a semistructured frame was used to ensure coverage of all the themes mentioned above. The interviews were transcribed verbatim. During the process, all identification information was either changed or deleted. The average length of the interviews was 97.6 min (min = 52, max = 157). The total duration of the data amounted to 33 h.

### **Analyses**

First of all, inductive thematic analysis (Braun & Clarke, 2006) was performed to detect repeated patterns across the dataset and to distinguish the main themes and sub-themes within and

between the stories. The validity of themes was tested by constantly matching them with the entire dataset. Further analyses were performed using thematic narrative analysis (Riessman, 2008). In this procedure, the aim is to evaluate meaning structures through the reconstruction of stories into more condensed forms (Brinkmann & Kvale, 2015). The primary goal was to synthesize the data and to identify core narrative elements. This was done by reading the transcripts multiple times, and by observing how previously coded themes- and sub-themes were associated with each other and with the stories as a whole. At the final phase, *story types* were arrived at by integrating the thematic contents of the stories, and by comparing the stories with each other. In all the analyses we attempted to maintain the phenomenological status of the participants' narratives by emphasizing their own experiences, and by avoiding excessive interpretations.

## Results

All the life stories included a phenomenon which, in the clinical context, was interpreted as either acute or prodromal psychosis. However, only 7 out of 20 participants actually used the term *psychosis*. Instead, they talked about a life crisis or a mental crisis. Other frequently used terms were *burnout*, *distress*, *mental health problem*, and *collapse*. All the participants indicated that their life-situation had eased since the time of their first contact with the mental health services. More specific demographic and clinical variables at the onset and at the time of the interview are presented in Table 1.

Based on the analyses, two types of stories emerged regarding how the crisis was included in the individual's life story: (i) *crisis as a disruptor of the normal life course* (N = 9), and (ii) *crisis as an expected reaction to life adversities* (N = 7). Four stories lacked continuous plots; hence, these stories were not fitted into either of the story types, even if thematic similarities occurred (see online supplements). When asked directly, these participants indicated that they had difficulties in remembering events prior and after the crisis.

**Table 1.** Demographic and clinical characteristics at onset and at the time of the interview.

Participants (N = 20)	
Demographics	
Age at baseline (MD/SD)	25/9
Age at the time of the interview (MD/SD)	45/11
Gender, male (%)	60
Marital status	
Single at baseline (%)	60
Single at the time of the interview (%)	70
Employment	
Unemployed at baseline (%)	25
Unemployed at the time of the interview(%)	50
Clinical characteristics	
GAS at baseline (MD/SD)*	38/15
Diagnosis at baseline**	
Schizophrenia (%)	55
Other non-affective psychosis (%)	30
Prodromal (%)	15
Neuroleptics	
At some point (%)	65
At the time of the interview (%)	35
Treatment contact at the time of the interview(%)	35
Disability allowances at the time of the interview (%)***	40

\*Rated at onset by a member of the treatment staff.

\*\*Diagnosis was made as the part of the Open Dialogue- research projects (see Seikkula et al., 2011).

\*\*\*Disability allowances granted due to decreased work capability caused by mental health problems

Note that the type stories in this study were used mainly to condense large amounts of data, and thus to act as an aid in reporting the data; hence, there were overlaps between the stories, and none of the themes were presented alone or in an exclusive manner.

### ***Crisis as a disruptor of the normal life course***

In these stories, the crisis was narrated as disrupting a plot that otherwise followed culturally normative or expected paths, including getting a job and starting a family. There were no singular traumatic events in childhood or before the onset, although many participants indicated that they were sensitive by nature and that this had made them vulnerable to distressing emotions. The crisis was often viewed as a consequence of multiple distressing life events, cumulative setbacks, or of significant changes in central life areas, breaking into the desirable life course:

*There were constant disappointments in our relationship and then that divorce thing happened. It affected my self-confidence, leading to other failures and disappointments. It was as if the house of cards that we had carefully built suddenly collapsed.*

Many participants said that prior to the crisis they had faced changes or other forms of distress in their relationships. These included also the death of a parent and other losses. In two stories the crisis was linked to childbirth (both participants having been diagnosed with postpartum psychosis). This was narrated as due to difficulties in adopting the mother's role. Another frequent sub-theme included adversities faced within intimate relationships. In women's stories, in particular, this was experienced as a threat, involving both physiological and psychological abuse:

*Back then my husband's nerves were constantly on edge and I and my children had to be afraid when he started yelling at us. I couldn't say anything or express my own thoughts. It was like a continuous stalemate situation, where we couldn't communicate. Finally I collapsed. I couldn't sleep and I started to feel that everybody wanted something bad for me.*

More often than women, men presented the crisis as a reaction to work-related disappointments, associated with constant stress, in addition to the fear of losing both the source of livelihood and the social respect of others:

*Prior my collapse, I worked so hard and I was sure that I'd get that promotion. However, they decided to hire another guy for that position, going right past me. It was horrible. I felt that they had mistreated me, and I started to think it was all just some kind of strange game.*

Life adversities were narrated as causing hopelessness and the fear that other people wanted to cause harm. Thus, beliefs interpretable as psychosis were often linked to actual life events, though in most of the stories, the attribution of someone's wish to harm was now regarded as an over-interpretation of circumstances, caused by distressing emotions. As a consequence, the crisis was narrated as a thoroughly confusing experience, characterized by a loss of control combined with the anxiousness and agitation.

On the other hand, even though these experiences were generally described as a distressing reaction to a hopeless life-situation, some participants viewed the sudden burst of energy in a more positive manner, when the experiences that followed it were more difficult to tolerate:

*In psychosis you really can't control your own actions and therefore you easily mess things up, but after that, I mean when you come back to this reality, it can be quite depressing. I started to sort of miss that psychosis: at least then I felt much lighter.*

As the mental health crisis was thematically linked to actual life events, it was narrated as easing simultaneously with changing life situations. Many participants also emphasized their own actions in the gradual process of surviving. Other factors that brought relief were also often found outside the actual mental health treatment, especially in relationships with significant others:

*Of course some people might benefit from treatment, I mean medication and stuff like that, but for me the most important thing was my friends and my family. It's just that someone listens to you, is interested in you, and is present.*

Overall, in these stories, life continued after the crisis. Most of the participants were able to continue with their jobs and to maintain other important life aspects. However, most of them also expressed regret, in that there was no going back to the time before the crisis, and that things had not worked out in their lives as they had expected:

*I imagined my life was going to be good, or at least normal, or something like that. You get a job, you have friends, but for me things didn't work out that way. Of course you still wish you could be a herd animal like others, but for some reason I always had those difficulties.*

In many stories, there was an observable conflict between one's personal experiences and the way things should have been or the way they are presented in general cultural narratives. Many participants also felt that they had become more vulnerable to psychological distress, and this had made them more cautious, especially in stressful life situations.

### **Crisis as an expected reaction to life adversities**

The stories in this category were characterized by significant life adversities occurring from early childhood. In many stories, these were associated with the social environment with a constant sense of divergence, and they were narrated as having had a significant impact on psychological well-being and on the participant's life course, years before any actual need for treatment. Given that such experiences had been recurrent from early childhood, the mental health crisis was presented as merely a peak representing dynamic processes of long duration. For example, some participants indicated that they had suffered from insecurity and a shattered sense of basic trust, related to their childhood environment:

*My father was very impulsive and short-tempered. I remember that there was this constant fear, and it lasted throughout childhood up to adolescence.*

Another frequent theme was *difficulties with peers*, which included bullying and other negative phenomena within close relationships. Many participants mentioned that bullying had had a negative impact on their psychological well-being, and in some stories, it was attributed as the primary cause of psychosis:

*In elementary school I was bullied constantly. So much that I wanted to kill myself. I think my psychosis started then, though nobody realized it. I started to hear their voices and I often saw those figures in the forest near our house, but when I got closer there was no one there.*

The bullying was mainly psychological, such as name-calling and exclusion from groups. In women's stories bullying was viewed as having had a severe impact on self-esteem, whereas in the men's stories aggression and the need to defend one's own rights were emphasized:

*I was bullied quite severely, and I think my mind somehow got stuck in the school premises. Eventually that led to a feeling that everything was a kind of a theater, and everybody was just faking and hiding some secrets from me. I developed those violent fantasies and I started to hear multiple voices, some were familiar and some were not. My mind was like a public toilet where all the townfolk were shitting.*

The experiences interpreted as a psychosis were associated directly with the adversities that occurred in the current social environment, here operating in a somewhat similar manner to the previous stories. In some stories, the disappointments faced in the social world were narrated as negatively affecting self-esteem, making interaction with others even harder. Some participants created meaning for their difficulties by viewing their personal characteristics as retarding their ability to gain independence, with the onset of the crisis narrated as a developmental crisis. Hence, there was no specific onset of crisis; instead, the entire shift from youth to adulthood was narrated

as causing psychological suffering, due especially to uncertainty regarding one's own identity and the future:

*I didn't know what I wanted to be or do, and I felt everybody else was making decisions for me. Those feelings and other difficulties were on a collision course, and I was driven to a stalemate situation, in which I didn't know what to do or how to react. Eventually that contradiction led to some kind of collapse of the mind.*

These stories were characterized by a distorted sense of reality, and some participants indicated that they were still not certain as to what was real and what was not. Many participants also indicated that during the acute phase of psychosis they had significant difficulties in interacting with others since they were so deep in their own reality:

*That psychosis was like you were sinking into some kind of a darkness where you couldn't find your way out. Like someone was pulling you down. I don't know what it really was.*

As described in the sample, such mental states were characterized by terror, though some participants viewed this as in some sense a relieving state of mind, warding off an even more horrifying reality:

*Of course it's scary when you constantly see those characters flying around you and hear those voices. But on the other hand it was a constant fight with my parents about what was real and what was not, as they attempted to wake me up to the real world, even though the real world was precisely what I was afraid of.*

Overall, in these stories, it seemed to be more difficult to get a grip of life after the crisis. In many stories, the experiences were repeated and strengthened, especially under stress, or in major life transitions. For these participants, such experiences – and mental health issues in general – seemed to form a more or less central element in their life story. Such an emphasis was understandable, given that the need for treatment and the time spent in mental health services in this group was higher, and that the age at onset was younger (see online data supplements).

As mental health issues were such a central part of these stories, it also seemed to be more challenging for the participant to evaluate how these had affected their life course. However, as compared to the previous stories, there were more attempts to view the consequences of the mental crisis in a relatively positive manner:

*Maybe without it (the psychosis) I wouldn't have those friends that are so important for me, but on the other hand, there are those negative things; I don't have a job, no education and, well, the coin always has two sides, right?*

## Discussion

In this study, people with lived experiences of severe mental crisis were actively given meanings to their experiences decades later of the initial need of treatment. In line with the earlier studies on narratives and psychosis, there was no single way of including these experiences within personal life stories, and further, basically, all the participants provided extensive narratives on how and why the crisis occurred, what it was like, and how it had affected their life course.

Despite the variety of narratives, many commonalities and recurring themes were found within and between the stories. For example, the majority of the stories were characterized by constant disappointments that had taken place in social environments, combined with sensitivity and low self-esteem. In some stories, the crisis was narrated as a combination of difficult emotions and over-interpretations, whereas in others it was characterized by the distortion of reality, and loosened self-control. People often seemed to make sense of such phenomena by linking them to a life-crisis, which formed an expected and inseparable reaction to actual life-events. Also, the factors that brought relief were narrated as deriving from real life, outside the actual treatment.

Some themes seemed to be linked to participants demographic characteristics. For example, in the women's stories, integrity was often insulted, while men with later onset presented the crisis in terms of a sense of inadequacy at being unable to provide a livelihood for the family. Participants



with earlier onset seemed to build their identities more specifically around their mental health crisis. Even though this might reflect symptom severity, and thus a higher need for treatment, it might also be consequence of the earlier onset itself. Thus, the crisis might have challenged the fulfilment of more traditional developmental paths, including education, getting a job and starting a family, with narrative identity then having to be built on a different foundation. Further studies would be needed on how such contextual factors affect the ways in which different experiences, including mental health issues, manifest themselves at particular times and within particular cultures, and how the experiences are interpreted.

There were also thematic unities in frequent themes. These manifested similarities to findings obtained from earlier studies on personal narratives (Barker, Lavender, & Morant, 2001; Judge, Estroff, Perkins, & Penn, 2008; Shepherd et al., 2012), and studies in which there was an emphasis on the role of adult and childhood traumatic experiences (Beards et al., 2013; Bentall, Wickham, Shevlin, & Varese, 2012; Isvoranu et al., 2017; Read, van Os, Morrison, & Ross, 2005; Sheperd et al., 2012), as well as personal sensitivity (Dudley, Siitarinen, James, & Dodgson, 2009). The enmeshed nature between the mental health crises and people's life experiences, and thus the need for more contextual perspectives, has been reported earlier (Gullslett, Kim, & Borg, 2014). As in our study, Jones, Kelly et al. (2016b) found that people with lived experiences of psychosis had sometimes challenges in defining the specific point of onset, presenting rather a continuity of themes and preoccupations from many years prior to the actual onset.

In addition, previous studies have emphasized the importance of moving away from distressing life events (Tan, Gould, Combes, & Lehmann, 2014), and the role of significant others (Pitt, Kilbride, Nothard, Welford, & Morrison, 2007; Tan et al., 2014) in the gradual processes of survival. Overall, it has been recognized that for persons with severe mental problems the crisis is not experienced as a single event or linear process (Gullslett, Kim, Andersen, & Borg, 2016).

Some differences from previous studies emerged. For example, in this study, the experiences towards the initial treatment were presented more neutral manner than have been reported in some studies (Thornhill, Clare, & May, 2004). The relative lack of the treatment-related narratives was somewhat unexpected, as the wish to get feedback on network-oriented treatment approach was expressed in the invitation. This might be partly due to the treatment approach itself, as it might have shift the whole initial treatment process closer to "real-life". Moreover, dialogical response to crisis might itself be beneficial (Seikkula, *in press*), enabling the creation of shared understanding and helping people to maintain their sense of agency (Holma & Aaltonen, 1997). Although the maintained sense of agency might partly explain why many participants in this study emphasized their own actions in survival, this issue merits further study. More information would also be needed on whether or not the different roles adopted in the clinical contexts could increase the risk of a self-fulfilling situations.

In addition, most of the stories in this study lacked the spiritual aspects of personal experiences presented in some earlier studies (e.g. Jones et al., 2016a). There are some possible explanations for this: in the first place, this could reflect factors related specifically to Finnish culture. It could also relate to the interview situation and the research setting as a whole, including potential selection bias. Nevertheless, the findings from different studies reflect the complexity of phenomena currently categorized under the term psychosis, underlining the importance of gaining more insight from people with lived experiences. This is especially important in the clinical context, as the participants indicated that they had had significant difficulties in expressing themselves during the initial crisis, with the major risk of their experiences being misunderstood by others.

Overall, in this study, people who had experienced a crisis diagnosable as psychosis commonly attempted to create meaning for their experiences by integrating the crisis with other life-course experiences; thus, they did not view it merely as a representation or symptom of a disorder. A similar gap between medical models and personal perspectives on the aetiology of psychosis has been reported previously, in studies on ageing individuals with a schizophrenia diagnosis (Bergman-Araten, Avieli, Mushkin, & Band-Winterstein, 2016; Ogden, 2014). This is despite the

common assumption that if a mental illness is viewed as similar to any other medical condition – a perspective often associated with an insight into the illness – this can help the patient to understand the nature of the disease and thus improve adherence to medication (e.g. Lacro, Dunn, Dolder, Leckband, & Jeste, 2002), with an eventual improvement in the outcome. However, it is notable that so far there have not been many studies including first-person accounts from persons who have *not* required mental health services or medication decades after the onset.

As one can presume that the stories might differ between persons who actively need and do not need treatment, in the present study the inclusion of both might have increased the validity of the findings. It should also be noted that, as compared to our earlier study (Bergström et al., 2018), the participant's clinical and demographic characteristics seemed to be representative of the entire FEP population in the catchment area in question. However, the high loss indicates that there was an selection, and more direct recruitment of those still in treatment could have increased the representation of people with who had experienced more severe crises (see Table 1).

There were also some other limitations. It is possible that the researchers' own preconceptions could have affected the course of interviews, and also the aspects focused on in the analysis. Even though all the participants were given the opportunity to review the transcriptions and to continue discussions afterwards, none of them wanted to use this opportunity, and it was therefore not possible to systematically review the analyses with them. In future, such opportunities should be given greater emphasis in the initial research protocol, in order to increase the validity of the analyses and to encourage service users to participate in the research and development of clinical practices. Here one should consider the possibility that in a researcher-led study of this kind some essential aspects of personal experiences were downplayed or simply misunderstood. One should further bear in mind that there are always both situation- and person-related factors affecting participants' decisions as to what they choose to bring up in interviews.

We attempted to compensate for some of these factors. Thus, we used a minimally structured interview protocol in order to reduce the possibility of leading questions or other researcher-related factors. In the analysis itself, the focus was only on what the participants themselves narrated, and excessive interpretation was avoided. It should be noted that all the participants were initially treated by following the principles of need-adapted and open dialogue approaches which emphasized their personal experiences, and this might have affected how their experiences were narrated. For example, it might have diminished the effect of treatment-related external factors including the traditional clinical or psychoeducational language on developing narratives. Finally, it is important to note that even though in interviews a semi-structured frame was used after the initial informal storytelling, causal relationships cannot readily be drawn from such data.

## Clinical implications

The use of a qualitative method makes it possible to increase understandings of how people themselves make sense of the psychosis phenomenon. This has potential in developing more person-centred treatment approaches that emphasize peoples' intentional and active role in meaning-making processes (see Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014), with possibilities for more beneficial treatment. For example, there are indications that needs-adapted and network-oriented treatment approaches – in which it is possible to collaboratively create and maintain the personal meanings of experiences – are associated with promising long-term outcomes in the treatment of psychosis (Bergström et al., 2018). A user-led investigation (Jones et al., 2016b) has also noted the need for approaches which take into account the complex nature of psychosis and that will emphasize the service user's own agency and experiences, rather than merely focus on symptom reduction and on pre-determined functional goals.

Overall, it is possible that a wide range of complex phenomena, currently categorized under the term psychosis, cannot be comprehensively treated as clear-cut symptoms of a particular disease entity, without reference to the context, including the patient's social and other "real-life"

environments. In addition, an increased awareness of the contextual and relative nature of experiences categorized as psychotic could offer more valid paths for research. In future, more robust studies are needed to obtain more generalizable knowledge on these issues.

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No potential conflict of interest was reported by the authors.

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## References

- Barker, S., Lavender, T., & Morant, N. (2001). Client and family narratives on schizophrenia. *Journal of Mental Health, 10* (2), 199–212.
- Beards, S., Gayer-Anderson, C., Borges, S., Dewey, M. E., Fisher, H. L., & Morgan, C. (2013). Life events and psychosis: A review and meta-analysis. *Schizophrenia Bulletin, 39*(4), 740–747.
- Bentall, R. P., Wickham, S., Shevlin, M., & Varese, F. (2012). Do specific early-life adversities lead to specific symptoms of psychosis? A study from the 2007 the adult psychiatric morbidity survey. *Schizophrenia Bulletin, 38*(4), 734–740.
- Bergman-Araten, T., Avieli, H., Mushkin, P., & Band-Winterstein, T. (2016). How aging individuals with schizophrenia experience the self-etiology of their illness: A reflective lifeworld research approach. *Aging & Mental Health, 20*(11), 1147–1156.
- Bergström, T., Seikkula, J., Alakare, B., Mäki, P., Köngäs-Saviaro, P., Taskila, J. J., ... Aaltonen, J. (2018). The family-oriented open dialogue approach in the treatment of first-episode psychosis: Nineteen-year outcomes. *Psychiatry Research, 270*, 168–175.
- Borchers, P. (2014). "Issues like this have an impact"—The need-adapted treatment of psychosis and the psychiatrist's inner dialogue. *Jyväskylän Studies in Education, Psychology and Social Research*, 507. Retrieved from [https://jyx.jyu.fi/bitstream/handle/123456789/44396/978-951-39-5861-9\\_vaitos25102014.pdf?sequence=1](https://jyx.jyu.fi/bitstream/handle/123456789/44396/978-951-39-5861-9_vaitos25102014.pdf?sequence=1)
- Boydell, K. M., Stasiulis, E., Volpe, T., & Gladstone, B. (2010). A descriptive review of qualitative studies in first episode psychosis. *Early Intervention in Psychiatry, 4*, 7–24.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.
- Brinkmann, S., & Kvale, S. (2015). *InterViews: Learning the craft of qualitative research interviewing*. London: SAGE Publications inc.
- Corstens, D., Longden, E., McCarthy-Jones, S., Waddingham, R., & Thomas, N. (2014). Emerging perspectives from the hearing voices movement: Implications for research and practice. *Schizophrenia Bulletin, 40*, S285–S294.
- Dudley, R., Siitarinen, J., James, I., & Dodgson, G. (2009). What do people with psychosis think caused their psychosis? A Q methodology study. *Behavioural and Cognitive Psychotherapy, 37*, 11–24.
- France, C. M., & Uhlin, B. D. (2006). Narrative as an outcome domain in psychosis. *Psychology and Psychotherapy, 79*(pt 1), 53–67.
- Georgaca, E. (2013). Qualitative research on the lived experience of psychosis: A methodological review. *Psychology, 20* (4), 397–412.
- Gullslett, M. K., Kim, H. S., Andersen, A. J. W., & Borg, M. (2016). Emotional darkness without solutions": Subjective Experiences of mental health crisis. *International Journal of Mental Health, 45*, 161–170.
- Gullslett, M. K., Kim, H. S., & Borg, M. (2014). Service users' experiences of the impact of mental health crisis on social identity and social relations. *Scandinavian Psychologist, 1*. doi:10.15714/scandpsychol.1.e2
- Holma, J., & Aaltonen, J. (1997). The sense of agency and the search for a narrative in acute psychosis. *Contemporary Family Therapy, 19*(4), 463–477.
- Isvoranu, A.-M., van Borkulo, C. D., Boyette, -L.-L., Wigman, J. T., Vinkers, C. H., & Boersboom, D. (2017). A network approach to psychosis: pathways between childhood trauma and psychotic symptoms. *Schizophrenia Bulletin, 43*(1), 187–196.

- Jones, N., Kelly, T., & Shattell, M. (2016a). God in the brain: Experiencing psychosis in the postsecular United States. *Transcultural Psychiatry*, 53(4), 488–505.
- Jones, N., Shattell, M., Kelly, T., Brown, R., Robinson, L., & Renfro, R. (2016b). “Did i push myself over the edge?”. Complications of agency in psychosis onset and development. *Psychosis*, 8(4), 324–335.
- Jones, N., Shattell, M., Kelly, T., Brown, R., Robinson, L., Renfro, R., . . . Luhrmann, T. M. (2016b). “Did I push myself over the edge?": Complications of agency in psychosis onset and development. *Psychosis*, 8(4), 324–335.
- Judge, A. M., Estroff, S. E., Perkins, D. O., & Penn, D. L. (2008). Recognizing and responding to early psychosis: A qualitative analysis of individual narratives. *Psychiatric Services*, 59, 96–99.
- Lacro, J. P., Dunn, L. B., Dolder, C. R., Leckband, S. G., & Jeste, D. V. (2002). Prevalence of and risk factors for medication nonadherence in patients with schizophrenia: A comprehensive review of recent literature. *Journal of Clinical Psychiatry*, 63(10), 892–909.
- Lysaker, P. H., & Lysaker, J. T. (2002). Narrative structure in psychosis – Schizophrenia and disruptions in the dialogical self. *Theory & Psychology*, 12(2), 207–220.
- McAdams, D. P. (2001). The psychology of life stories. *Review of General Psychology*, 5(2), 100–122.
- McCarthy-Jones, S., Marriot, M., Knowles, R., Rowse, G., & Thompson, A. R. (2013). What is psychosis? A meta-synthesis of inductive qualitative studies exploring the experience of psychosis. *Psychosis*, 5(1), 1–16.
- Ogden, L. P. (2014). “My life as it is has value”: Narrating schizophrenia in later years. *Qualitative Health Research*, 24(10), 1342–1355.
- Pitt, L., Kilbride, M., Nothard, S., Welford, M., & Morrison, A. P. (2007). Researching recovery from psychosis: A user-led project. *Psychiatric Bulletin*, 31, 55–60.
- Putnam, L. (2018). A license to be crazy. *Journal of Humanistic Psychology*. doi:10.1177/0022167818773914
- Read, J., van Os, J., Morrison, A. P., & Ross, C. A. (2005). Childhood trauma, psychosis and schizophrenia: A literature review with theoretical and clinical implications. *Acta Psychiatrica Scandinavica*, 112, 330–350.
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. USA, CA: SAGE Publications.
- Roe, D., & Davidson, L. (2005). Self and narrative in schizophrenia: Time to author a new story. *Medical Humanities*, 31(2), 89–94.
- Roe, D., Hasson-Ohayon, I., Kravetz, S., Yanos, P. T., & Lysaker, P. H. (2008). Call it a monster for lack of anything else. Narrative insight in psychosis. *The Journal of Nervous and Mental Disease*, 196(12), 859–865.
- Rose, D. (2017). Service user/survivor-led research in mental health: Epistemological possibilities. *Disability & Society*, 32(6), 773–789.
- Seikkula, J. (in press). Psychosis is not illness but a survival strategy in severe stress: A proposal for an addition to a phenomenological point of view. *Journal of Psychopathology*.
- Seikkula, J., Alakare, B., & Aaltonen, J. (2001). Open Dialogue in psychosis I: An introduction and case illustration. *Journal of Constructivist Psychology*, 14(4), 247–265.
- Seikkula, J., Alakare, B., & Aaltonen, J. (2011). The comprehensive open-dialogue approach in Western Lapland: II. Long-term stability of acute psychosis outcomes in advanced community care. *Psychosis*, 3, 192–204.
- Shepherd, S., Depp, C. A., Harris, G., Halpain, M., Palinkas, L. A., & Jeste, D. V. (2012). Perspectives on schizophrenia over the lifespan: A qualitative study. *Schizophrenia Bulletin*, 38(2), 295–303.
- Tan, R., Gould, R. V., Combes, H., & Lehmann, S. (2014). Distress, trauma, and recovery: Adjustment to first episode psychosis. *Psychology and Psychotherapy: Theory, Research and Practice*, 87, 80–95.
- Thornhill, H., Clare, L., & May, R. (2004). Escape, enlightenment and endurance – narratives of recovery from psychosis. *Anthropology & Medicine*, 11(2), 181–199.