

**Understanding the trauma gap in severe mental distress: A narrative study  
of individuals with sensitivity to psychosis**

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## Abstract

Even though there is a high prevalence of trauma in psychosis, trauma often remains ignored and undertreated in mental healthcare. Accumulating evidence suggests that trauma care in psychosis is as effective and safe as in other populations. Nevertheless, there is little understanding on the experiences of individuals with sensitivity to psychosis on trauma-informed care. Therefore, the aim of this narrative study was to explore what kind of trauma-informed care individuals with sensitivity to psychosis seek and receive, and how they perceive their trauma-informed care.

An existing data set of stories about personal recovery formed the basis of this study. The stories were collected through the “Psychiatry Story Bank”, a project started by the department of psychiatry of the University Medical Centre of Utrecht (The Netherlands). This study focused on a subgroup of the initial project: participants who experienced multiple episodes of psychosis, experienced trauma, and were seeking trauma-informed care. The participants shared their story through an open interview. In total, five stories were analysed based on holistic content analysis.

The results corroborate the initial assumption that trauma in psychosis is often ignored and undertreated in mental healthcare. The participants were looking for acknowledgement of their trauma, in order to receive care for this. However, they experienced that mental healthcare often did not pay attention to their trauma. When trauma was acknowledged, the participants were often refused care and did therefore not receive the desired trauma-informed care from mental healthcare. As a result, the participants sought their own trauma-informed care. Despite the differences in the kind of care they ended up with, which was quite varied, all participants told about a journey in finding appropriate care. Their search could involve mental health care and therapy treatments, but often moved outside of mainstream psychotherapy. All forms of care involved a good therapeutic relationship, which seems to be an important factor of why all self-sought care is perceived as effective.

This narrative study provides a contribution to a better understanding of what individuals with sensitivity to psychosis seek in trauma-informed care and receive, but also how this is perceived. The findings point out the importance of professionals to focus on psychological processes underlying psychosis and to treat trauma in individuals with sensitivity to psychosis, with more attention to the therapeutic relationship in order to positively affect treatment outcomes.

## **Introduction**

There is high prevalence of trauma in psychosis, however, trauma often remains ignored and undertreated in mental healthcare (Lommen & Restifo, 2009). It is suggested that trauma treatment in psychosis is as effective and safe as in other populations (Van den Berg et al., 2016b). Nevertheless, there is little understanding on helpful aspects of trauma treatment from the perspective of individuals with sensitivity to psychosis. In response to research demonstrating that trauma is widespread across society and that it is highly correlated with mental health, trauma-informed care emerged (Sweeney et al., 2018). The fundamental shift in providing support using a trauma-informed approach is to move from thinking ‘What is wrong with you?’ to considering ‘What happened to you?’. Trauma-informed care is a process of organisational change that creates recovery environments and relationships for practitioners, individuals with mental disorders, their friends and allies, with prevention of retraumatisation. To be trauma-informed is to understand the involvement and impact of trauma in the lives of most consumers of mental health and to apply that understanding in providing services and designing service systems so that they accommodate the needs and vulnerabilities of individuals and facilitate their participation in treatment (Butler et al., 2011). This trauma-informed care can be a first step towards reporting and treating trauma in individuals with sensitivity to psychosis.

In this qualitative study, trauma-informed care from the experiences of individuals with a sensitivity to psychosis is addressed. Within literature, reference is mainly made to regular care practices when trauma-informed care is discussed, however, there is growing attention for alternative care practices. In this study, trauma-informed care includes both regular and alternative care practices. The aim of this study is to explore what kind of trauma-informed care individuals with a sensitivity to psychosis seek and receive, and how they perceive their trauma-informed care.

### **Trauma in psychosis**

There is already a large body of research examining the prevalence and clinical correlates of posttraumatic stress disorder (PTSD) in the general population (Grubaugh et al., 2011). The World Health Organization (WHO) reports that 70% of the general population have experienced trauma exposure consistent with DSM-5 criterion A of PTSD (American Psychiatric Association, 2013), with an average of 3.4 trauma exposures per individual (Kessler

et al., 2017). However, trauma does not lead to PTSD in most cases. The DSM-5 classifies a traumatic event as that in which an individual is exposed to “actual or threatened death, severe injury or sexual violence” (American Psychiatric Association, 2013). Exposure to a traumatic event is disturbing as it can lead to mental and emotional distress (Kessler et al., 2000), and individuals can suffer from symptoms for several years after initial exposure (Gold et al., 2000).

Hence, studies have demonstrated that there is high incidence of trauma in general. However, trauma has been found to commonly co-occur with psychosis (Varese et al., 2012). Psychosis affects approximately 3% of the general population (Perälä et al., 2007) with the two most common symptoms being hallucinations (perceptions occurring in the absence of external stimuli, such as hearing voices that other people cannot hear) and delusions (fixed, false beliefs) (Arciniegas, 2015). The systematic review of Seow et al. (2016) found that the majority of the studies about comorbid PTSD in psychosis have reported prevalence rates in the range of 20-30%. Therefore, there are many individuals with sensitivity to psychosis who suffer from symptoms of their experienced trauma.

The link between trauma and psychosis is complex and multifactorial with different proposed pathways (Morrison et al, 2003). The first link includes psychosis as a result of childhood adversity, e.g., sexual, physical or emotional abuse (Varese et al., 2012). The second link includes trauma as a result of psychotic symptoms or treatment experiences (Buswell et al., 2021). The experience of psychotic symptoms, such as distressing hallucinations and associated treatment responses including involuntary hospitalisation and forced medication, can be perceived as traumatic which can lead to the development of PTSD (Paksarian et al., 2014). The third link includes psychosis and PTSD as related types of reaction to trauma (Morrison et al, 2003). There is significant overlap in the symptoms of psychosis and PTSD, and both incorporate a distinction between “positive” (e.g., hallucinations, flashbacks) and “negative” symptoms (e.g., diminished emotional expression, feelings of detachment from others) (O’Conghaile & DeLisi, 2015). The complex link between trauma and psychosis might complicate the understanding of the mental disorders and its diagnosis.

Unfortunately, both trauma exposure and its diagnosis are often underreported in routine care, despite the high prevalence of trauma exposure in individuals with sensitivity to psychosis (Lommen & Restifo, 2009). Individuals with sensitivity to psychosis are often not assessed for trauma disorders (Read et al., 2017). More specifically, their research indicates that individuals with sensitivity to psychosis are less likely to be asked questions about trauma in initial assessments than individuals with other diagnoses. Due to the nature of psychosis, there are

concerns that individuals with sensitivity to psychosis may not be able to accurately report on their traumatic memories and associated symptoms (Grubaugh et al., 2011). Their research states that most instruments for assessing traumatic event exposure and trauma-related symptoms were not initially normed on psychosis. However, the findings of Grubaugh et al. generally support the reliability and validity of trauma assessments conducted in this population. Their data suggest that individuals with sensitivity to psychosis are able to accurately report on their traumatic event histories and associated symptoms. It is important for practitioners to use these instruments to assess trauma-related symptoms in individuals with sensitivity to psychosis as undiagnosed trauma disorders prevents access to appropriate treatment, impeding recovery from psychosis or leading to additional comorbidities such as anxiety and depression, substance abuse, and suicidality (Mueser et al., 2010).

In addition to underreporting trauma, individuals with sensitivity to psychosis are often refused trauma-informed care, according to Roconi et al. (2014) who studied this in the United States. In most of these cases, practitioners are reluctant to use trauma-informed care in individuals with sensitivity to psychosis (Frueh et al., 2006; Meyer et al., 2014). Based on literature, Van den Berg et al. (2016a) studied types of practitioner beliefs as reasons for this reluctance. Some practitioners consider findings of the efficacy of evidence-based treatments of little value to their clinical practice (Foa et al., 2013). Other practitioners believe that certain care are burdensome for individuals with sensitivity to psychosis and practitioners. Trauma-informed care can be burdensome for both these individuals and practitioners, even though these individuals consider it to be tolerable and would undergo treatment again (Deville & Spence, 1999). Some practitioners have this (often non-empirically supported) belief that trauma-informed care will destabilize individuals with sensitivity to psychosis and worsen symptoms, which can lead to various adverse events, e.g., crisis, suicide attempts, hospitalization, and dropout (Foa et al., 2002; Van Minnen et al., 2010). However, the reality is that increase of trauma-related symptoms in trauma-informed care is rare and, when it does occur, it is often temporary and unrelated to treatment response (Foa et al., 2002). Practitioners' reluctance leads to unnecessary refusal of trauma-informed care of individuals with sensitivity to psychosis, impeding recovery from trauma as well as psychosis.

## **Experiences of psychosis sensitive individuals with trauma-informed care**

Therefore, much research has already been done on understanding the link between trauma and psychosis, as also on underreporting and undertreatment of trauma in psychosis and its reasons. However, research about trauma-informed care for individuals with sensitivity to psychosis is scarce, since these individuals are frequently excluded from trauma-informed care (Ronconi et al., 2014) and randomized clinical trials of trauma-informed interventions (Mueser et al., 2002; Van den Berg et al., 2016a). As a result, individuals with sensitivity to psychosis are underrepresented. Only few research studied the effectiveness of trauma-informed care for individuals with sensitivity to psychosis. Research of Sin and Spain (2017) suggests that trauma-informed care with direct trauma memory processing are particularly effective in reducing trauma-related symptoms in individuals with sensitivity to psychosis. Prolonged exposure and eye movement desensitisation and reprocessing (EMDR) were found to be effective, safe, and feasible in individuals with sensitivity psychosis and comorbid trauma (Van den Berg et al., 2016b). With both trauma-informed care significantly more individuals achieved remission from psychosis. These results suggest that trauma-informed care with direct trauma memory processing has long-term neutral to positive effects on symptoms of trauma and psychosis. Despite the emergence of research into trauma-informed care, it is still unknown why and how this care is perceived as helpful by individuals with sensitivity to psychosis. Hence, more qualitative research is needed on what these individuals experience as helpful in trauma-informed care and how this kind of care should be designed. This knowledge could help produce more adequate care protocols (Mueser et al., 2002), and consequently improve care aimed at recovery from trauma and psychosis. Moreover, research of Shay and Lafata (2015) indicates that considering individuals' perspectives on mental disorders, care, and recovery has been known to affect outcomes, and is therefore important to study.

In one of few studies where the individuals' perspective went beyond treatment effectiveness, the individuals argued for the need for trauma-informed care to focus on psychological processes underlying psychosis instead of only its manifestations, and that individuals with sensitivity to psychosis are also keen to use such services (Hobfoll et al., 1995). Wood et al. (2019) studied individual and practitioner perspectives on the care priorities of psychiatric in-patients with sensitivity to psychosis. Their findings indicate that there are gaps between individuals with sensitivity to psychosis and practitioner perspectives on important priorities for in-patient care as these individuals want to incorporate trauma into their treatment and rather focus on the distress resulting from symptoms, whereas practitioners reported the

primary purpose of in-patient care being to reduce symptoms and risk reduction. Although these qualitative studies indicated the importance of individuals to incorporate trauma into their treatment, they still do not specify individuals' experiences on helpful aspects of trauma-informed care. Therefore, insight is needed into how these underrepresented individuals make sense of trauma-informed care. In conclusion, trauma often remains ignored, underreported, and undertreated in mental healthcare (Lommen & Restifo, 2009). However, accumulating evidence suggests that trauma treatment in psychosis is as effective and safe as in other populations (Van den Berg et al., 2016b). Nevertheless, there is little research on perceived helpful aspects of trauma-informed care. Therefore, deeper insight is needed in the experiences and needs of individuals with sensitivity to psychosis themselves, in order to bridge the gap in current literature and to increase trauma-informed care. Hence, the research question of this study is: What kind of trauma-informed care do individuals with sensitivity to psychosis seek and receive, and how do they perceive their trauma-informed care?

## **Method**

### **Setting**

An existing data set of stories about personal recovery formed the basis for this study. The stories in this data set were collected through the "[Psychiatry Story Bank](#)", a project started by the department of psychiatry of the University Medical Centre of Utrecht (The Netherlands). Service-users, their loved-ones and (informal) caregivers are invited to share their stories in an open interview as part of this initiative. The aim of the project is to use personal stories to improve psychiatric care and recovery support. This study focused on the stories of a subgroup of service-users to analyse personal recovery.

### **Participants and data selection**

Participants of the project were individuals that made use of psychiatric services in the Netherlands. Initially, participants were recruited on the basis of convenience sampling. Individuals could sign up through the project website, which was advertised on (social) media, at conferences, and through word-of-mouth.

This study focused on a subgroup of service-users of the initial project. Participants of this subgroup were selected on the basis of three selection criteria: (a) living with a sensitivity

to psychosis, (b) self-reporting trauma, and (c) seeking trauma-informed care. Exclusion criteria was single episodes of psychosis. The project Psychiatry Story Bank consisted, at the time of this study, of 228 interviews. First, the interviews of individuals who have experienced multiple episodes of psychosis were selected from the interviews of all service-users. These were twenty-eight interviews. Second, from this sample, interviews in which individuals explicitly refer to having experienced trauma, with or without providing further details, were selected. This method resulted in inclusion of seventeen interviews. In the non-selected interviews, trauma was not discussed by the individuals. Therefore, the interpretations of the individuals were leading in the identification of trauma. Finally, from this sample, five interviews were selected in which trauma-informed care was discussed. In making this distinction, attention was paid to whether care was sought and if this care was specific to trauma. With this selection method, participants are included who have framed their problems in terms of trauma and are willing to confront it and take action to seek care. In the non-selected interviews, care was sought for psychosis and not for trauma, or it was not clear what care was sought for. Therefore, with this final sample, five participants were selected.

The sample consisted of three females and two males, whose age ranged between 46 and 52 years. Two of the participants were diagnosed with bipolar disorders, two participants with schizoaffective disorder, and one participant with unspecified psychotic disorder. The number of admissions ranged from one to seven. Only one participant is diagnosed with PTSD. Three of the participants have completed university education, and two of the participants have completed higher vocational education.

## **Interview**

The aim of the project Psychiatry Story Bank is to invite service-users, their loved-ones and (informal) caregivers to share their stories through an open interview. The goal of this open interview was to improve psychiatric care and recovery support, through the study of personal stories. The participants were encouraged to guide the direction of the interview with the opening question: “What story would you like to share?”. The participant’s conversation was interrupted or interfered with questions by the interviewer as little as possible, only to provide depth and fill in gaps. The interviews were administered by a trained interview pool of junior mental healthcare professionals. All interviewers were trained and supervised by the project



team during data collection. After their first unsupervised interview, the quality of the interview was systematically evaluated, and desirable techniques and pitfalls were discussed.

## **Procedure**

After signing up for the project, participants were informed about the aim and process of participation through phone. Afterwards they received an information letter about the study and the way their personal data would be treated. All participants provided their written informed consent. The interviews were administered between May 2018 and March 2022. Interviews lasted 60-90 minutes. All interviews were audio taped, transcribed literally and anonymously, and stored in a secured data base in an anonymous form.

An experience expert from the project team educated the interviewers in terms of recovery support to ensure that participation in the project would be a recovery support experience. In addition, all participants were given the opportunity to receive an edited and anonymised summary of their story published on the online platform. The platform is aimed to make story sharing personal and socially beneficial for both the narrator and the recipients. Subsequently, participants were asked to fill out an evaluation form.

## **Data analysis**

The data set consisted of already transcribed interviews. The holistic content analysis (Lieblich et al., 1998) was used to analyse the interviews. This analysis ensures that the personal story of each participant would remain intact. Holistic content analysis includes a general impression and the themes. The general impression of Lieblich et al. (1998) is modified according to Ditzel (2019) in order to fit this research, and consisted of three components: (1) a short summary of the background story of the participant, related to his/ her journey through mental healthcare, (2) an impression of the person, about the story the participant wants to tell and his/her experienced trauma, and (3) the impression the researcher got of the participant based on the interview, for instance the resilience of the participant and what the participant encounters as it might represent the participants' journey to recovery. Verbal behaviour was considered for the impression based on the interview. Since the researcher was not present during the interviews, the researcher was dependent on verbal behaviour. A positive psychological lens, opposed to one informed by psychopathology, was applied to the stories of

the participants. Attention was paid to their qualities and strengths. This brought an appreciative perspective to the analysis, and explains the focus on the resilience of the participants. However, vulnerabilities were also looked at and were incorporated based on what the participants encounter and experience as tough. The holistic content analysis uses an inductive analysis method to determine the themes. This means that the derived themes of this study are based on the data of the interviews, using the researcher's implicit knowledge of mental health and focus on data related to trauma-informed care.

The process for analysing the interviews in terms of the holistic content analysis can be summarized as follows: The interviews were first read several times until the foci of the whole story with regard to trauma-informed care emerged. The researcher took notes about her initial and overall impression, along with recurring topics. A focus could be characterized by a large amount of information, much detail or repetition devoted to a certain topic within an interview. Hereby, the researcher concentrated especially on the different themes of trauma-informed care. The process of naming the themes to represent the core of the theme was complicated and raised doubts about the names of the themes. The researcher aimed to relate the names of the themes to the research question while the names of the themes were close the participants' words. This resulted in unique themes for each participant. Based on these initial themes, the interviews were colour coded for each of their foci separately. During revision of the coding scheme, it was noticeable that some themes could be split into two themes and therefore themes were added. For example, Mary's theme "Desire to understand oneself" has been divided and the theme "Own research into recovery" has been added. When dividing the content between the themes, it was difficult to determine which content belonged to which theme as the content was often intertwined. After this step, comparative analysis of themes across interviews was used and similarities in the content of themes were noticed. Therefore, the names of the corresponding themes were revised and put in the same order to create a more uniform set of themes. For example, John's theme "Ignored trauma" was originally called "Valediction to mental healthcare". Some themes have also been renamed to better match all content of the themes. For example, the universal theme "Self-sought care" was originally called "Alternative help". However, this comparative analysis did not result in the exact same themes for all participants, but in variation in which themes were present in some interviews but not in others. Hence, there is attention to systematicity but also to uniqueness. With this final coding scheme, the themes covered only a part of the interviews. The parts that were not covered were content

about psychosis and its treatment. At the end of the analysis, titles of the stories were decided. The titles were chosen based on a quote that best reflects the participant's story.

## Results

First, to give an impression of the interviews, the portraits of the five individual participants are presented. Next, a description is given of the themes in relation to their trauma-informed care they sought and received. The used names are pseudonyms, in order to make their story more personal. Table 1 includes an overview of the titles of each story and the different themes mentioned per participant.

### **“Mary”: “I felt misunderstood in mental healthcare”**

The first participant is a woman in her fifties, Mary. Mary is diagnosed with bipolar disorder, type 1. She has experienced psychosis twice. Mary experienced her psychosis as “radical”. During one of these psychoses, she was admitted into a psychiatric hospital. At that time, Mary was prescribed medication, and she was also taking medication at the time of the interview. Mary has experienced trauma. She has received regular mental health care for both psychoses and traumatic events. She has not been diagnosed with PTSD. Mary has completed a university education.

Mary said she wanted to share her story about how she deals with her diagnosis, what she encounters in regular mental healthcare and how she finds her own way around it. Mary explained that she suffers from early childhood trauma: "I have memories of my birth time. I was born as a premature baby [...]. I was in an incubator for six weeks. I was not wanted as a baby". This has consequences in her daily life: "I suffer from chronic sleeping problems and startle reactions. My whole body is in a kind of panic. My body will start to settle. Especially with intimacy. When I am touched, I cannot stand it". Mary saw her trauma as an explanation for her psychoses. However, her psychiatrist disagreed and indicated that there were no regular care practices for early childhood trauma. Mary then went in search of therapists herself, but they refused her as well. Moreover, Mary also experienced trauma at a later age, but she did not talk about that during her interview.

Throughout the interview, Mary appeared as a resilient person. She had experienced several setbacks in mental healthcare. However, she did not leave it at that and sought care

**Table 1***Overview of themes per participant and their titles*

<b>Participant</b>	<b>Title of story</b>	<b>Themes</b>
Mary	“I felt misunderstood in mental healthcare”	Ignored trauma Refused trauma-informed care Desire to understand oneself Own research into recovery Self-sought care
Jennifer	“A psychosis does not appear from nowhere”	Ignored trauma Refused trauma-informed care Self-sought care Humaneness
John	“If this is what [regular] mental healthcare has to offer, I will figure it out myself”	Ignored trauma Desire to understand oneself Own research into recovery Self-sought care
David	“Mental healthcare did not offer much, just medication in fact”	Ignored trauma Self-sought care
Susan	“Trauma underlies the beliefs I had in psychosis”	Ignored trauma Self-sought care Humaneness

herself. Mary shows that she has her sensitivity to psychosis under control: "I have recovered well from my psychoses. I work for 32 hours a week. But sometimes I do have a dip. Then I work a little less and save my energy. I will remain sensitive to episodes". Mary seems to be an optimistic person, despite her setbacks and current struggles with her sensitivity to psychosis. She has already developed herself and is satisfied with her way of life, but Mary also indicated that she wants to develop further.

### ***Ignored trauma***

In Mary's interview, the theme of ignored trauma came to the fore in one situation, where she factually describes the situation with her psychiatrist. Unlike Mary's other themes, in this theme she depicts something of her inner world. This theme is a key focus in her interview. Mary described her experience with trauma in psychosis: "During my first psychosis, I noticed that the psychosis had something to do with early childhood trauma. It seemed like all kinds of memories were awakening". After this psychosis, she delved into early childhood trauma and, after reading various scientific studies, Mary found out that there is a relationship between trauma and bipolar disorder. Mary discussed this with her psychiatrist, who denied that there was a relationship between trauma and bipolar disorder. Mary said: "I did not believe it. I did not feel understood there". This information characterizes Mary's theme in that the psychiatrist denied the relationship between trauma and psychosis, in addition to ignoring that trauma. Mary was not assessed for trauma by mental healthcare, so she had to address her trauma herself. Despite reporting the effect of trauma on Mary's psychosis to a professional, the relationship between her trauma and her psychosis was still ignored. Therefore, it seems that Mary was seeking for acknowledgement for her trauma and someone who would take the relationship between her trauma and psychosis seriously.

### ***Refused trauma-informed care***

The theme of refused trauma-informed care emerged throughout Mary's life and interview. First, it emerged as a phase in her life explaining the different situations where she was repeatedly refused. It then emerged as what this phase means for her daily life at the moment. It is noticeable that Mary mainly tells factual information and gives little information about her inner world. What is distinctive of her way of experiencing refusal of care is that she

has been refused by several professionals, each time out of fear of being disrupted by psychosis. This theme is the key focus in her interview. Mary described the trauma-informed care she sought:

I have asked my psychiatrist several times about treatment options for early childhood trauma. But he replied that there were no existing treatment options and could not offer me any treatment. So, I went to the general practitioner who would refer me. However, I had to look myself for an EMDR practitioner who was specialized in early childhood trauma. I have approached five or six practitioners. They told me that they thought the risk was too great because I am sensitive to psychosis. So, they will not treat me. Finally, I found one practitioner who was optimistic. Ultimately, this practitioner also refused treatment because my psychiatrist did not support it. He said that it was not wise to stir up all that old sorrow.

Mary said she wanted trauma-informed care for her early childhood trauma, but she was not supported by the mental healthcare. She did receive EMDR treatment for traumas she developed later in life: "This has brought me some peace. But EMDR has not solved my problems that I experience, a chronic sleeping problem and violent shock reactions during intimacy". Hence, Mary was keen to receive trauma-informed care for her early childhood trauma, which took the relationship between her trauma and psychosis seriously. However, her request for care was refused by multiple professionals out of fear for the consequences of this for her psychosis. This refusal means that Mary she does not receive the care she was looking for and can therefore not recover from the symptoms from her early childhood trauma.

### *Desire to understand oneself*

In Mary's interview, this theme appeared in different meanings where she discussed why the theme is important to her. In addition, the theme also emerged in a situation where she talked about different forms of care in which she wanted to understand herself better. In this theme Mary showed little of her inner world. What is characteristic of this theme of Mary is that Mary herself actively sought ways to better understand herself. This theme is discussed by Mary in the interview as additional information. It is important for Mary to understand herself. She narrated that she likes to understand what is happening but also what causes the psychoses. She said: "If I am triggered by some things, that I react so strongly to them, what is that and how can I ensure that that intensity decreases? So that I also become less susceptible to

psychosis". Mary explained she would also like to look at factors that help to process emotional information and to prevent psychosis in stable periods. However, Mary experienced that she could not get this information from her psychiatrist: "If it concerns what is behind it and what causes it, then I should not be with him". Mary has been actively working on understanding, also to understand the relationship between trauma and psychosis with regard to herself:

After the first psychosis I tried healings and readings to find out what the truth is, because during the psychosis I relived my birth time. And then you can say that it is not possible ... But I have physical sensations, very intense startle reactions.

Mary experienced that only a limited number of explanations were looked at within mental healthcare, while according to her, there are more possible explanations for her problems that are not seen. Mary narrated that there is more attention for early childhood trauma in scientific literature, and she would like to see that these underlying causes and explanations are given more attention within mental healthcare. She said: "There is knowledge, but not yet in practice. Only with a few, but they are busy. They have a waiting period of two years". Thus, Mary felt the need to understand the causes of her psychosis in order to recover from her psychosis. She was seeking for this information from mental healthcare, however, she could not gather this information from professionals to satisfy her need and therefore had to research it herself.

### *Own research into recovery*

Mary's theme own research into recovery is discussed in one meaning, explaining her research, and appeared at different situations in her life. In this meaning, Mary's hoped for recovery through her own research are reflected. Her hope of recovery through explanatory models is also what characterizes Mary's theme. This theme is discussed as side information in her interview. After Mary better understood her psychosis and possible explanations, she has done more research into recovery. She said:

Every time I was disappointed again, I bought four more books. I went to read them to see if there really were no options left. In this way I expanded my knowledge. More explanatory models are possible than the regular explanatory model. Interesting about many explanatory models is that when I have more models, my options for recovery

also increase. This way there are still possibilities for me, while someone else thinks there are no treatments left for me.

She researched a number of explanatory models, namely looking from the perspective of biology and body-orientation as well as energy. Mary was given a restricted explanation from mental healthcare: "They were like you have a condition, based on a biological explanation. If they think something is purely biologically based on brain function, then of course they will also look for a solution there, such as medicines". Mary experienced that mental healthcare only looked at a biological explanation for her complaints. Based on this explanatory model, Mary was refused care, which left her disappointed multiple times. As a result, Mary looked for other explanatory models in order to increase the possible forms of care. This gives the impression that she had put her hopes in other explanations in order to be able to recover from her complaints, since the used explanation of mental healthcare deprived Mary her hope of recovery.

### *Self-sought care*

In Mary's interview, the theme of self-sought care came forward in multiple situations in her life and interview, where she mentioned the different types of care she sought, explained these types of care and its effectiveness. What is unique of Mary's theme is that the care is focused on early childhood trauma, in which she noticed that regular care was not appropriate and therefore looked for alternative care. This theme is an important focus in Mary's interview. Mary explained the alternative care she sought after refusal from regular mental healthcare: "I have done things like shiatsu massage. I have been trained in shamanism. That also helped me a lot". Mary explained: "Early childhood trauma often involves dissociation. A shaman is trained to look for thoughts that have gone away, to find out where they have gone. It is a good method to get in touch with child parts of yourself". Mary has also read in scientific articles that trauma is stored in the body. She described: "You have to see if you can complete the movement or if you can vibrate out the tension that is in your body. You can think of trauma release exercises or somatic experience. I did that too". Mary has therefore had psychological care from regular mental healthcare but has also actively sought solutions herself. She experienced this as disturbing: "I am not always supported by the mental healthcare. They do not think along with me. I had to figure it out myself. I feel misunderstood". Mary described: "I am sorry that I cannot get further care with the relationship with trauma within mental



healthcare”. After Mary was refused trauma-informed care from mental healthcare, she sought care herself. In these forms of care, she was in touch with her trauma and able to reflect on it, both with the help of her thoughts and with her body. Mary gave the impression that she experiences these forms of care as helpful.

### **“Jennifer”: “A psychosis does not appear from nowhere”**

Jennifer is a woman in her fifties. She is diagnosed with a bipolar disorder. Jennifer is admitted into a psychiatric hospital three times for psychosis. During Jennifer’s first admission, she was prescribed medication and was still taking medication on the day of the interview. Jennifer experienced several traumatic events. Jennifer has not been diagnosed with PTSD. She has received regular mental health care for her psychoses and is currently receiving trauma-informed care for her traumatic events. Jennifer has completed a higher vocational education.

Jennifer said she wanted to share her story to make clear that a psychosis does not appear from nowhere. She also narrated she wanted to indicate that the attitude of the mental healthcare providers was not helpful in her recovery. Jennifer does not delve deeply into her traumatic life experiences. She explained: “I had a traumatic childhood. I have been abused”. She continued: “My son has also been abused. This surfaced during my psychoses”. Jennifer said: “These traumatic events have a clear cause for my psychoses”. However, mental healthcare did not pay attention to this, and she therefore did not receive any trauma-informed care. Moreover, Jennifer experienced her psychoses and admissions as “traumatic”. She does not elaborate on this either. In the end, Jennifer sought a therapist herself and is now engaged in trauma-informed care.

During the interview, Jennifer came across as a strong person. She has had several setbacks in her life and from the mental healthcare sector. However, she then looked for trauma-informed care herself. Jennifer has been able to transform the unpleasant experiences into something positive, as she gives lectures where she can help others and share what she missed during her recovery process, while she is working hard on herself through trauma processing.

### ***Ignored trauma***

In Jennifer’s interview, the theme of ignored trauma came forward in multiple situations in her life and is discussed in different situations throughout the whole interview, where she described that there was no attention for trauma from mental healthcare and that the focus was

mainly on symptom management of the psychosis. Jennifer often narrates this factually, but between the lines the frustration and sadness came to the fore. What is characteristic of Jennifer's theme is that by ignoring the trauma she got the feeling that she was not allowed to speak discuss her trauma, while she wanted to. This theme is a key focus in Jennifer's interview. Jennifer has experienced several traumatic experiences. She explained that she felt the need to talk about these experiences. She has noticed that those traumatic experiences were not taken into account within mental healthcare. Jennifer experienced that there was little to no room to talk about these experiences. Jennifer told: "In a psychosis I ran off with traumatic experiences. We hardly talked about that within the mental healthcare. While that is something one should talk about". She noticed that the care was aimed at symptom control. She was not assessed for trauma and experienced that mental healthcare did not want to look at the causes of psychosis. Throughout the interview, Jennifer gave the impression that she felt as if it was not desirable or impossible to talk about trauma within mental healthcare, while she seemed eager to discuss her trauma since it was an important factor during her psychosis. This made Jennifer feel "ignored" by mental healthcare.

### ***Refused trauma-informed care***

This theme of refused trauma-informed care came forward in one situation in her life and is discussed in Jennifer's interview once. Jennifer factually talks about this information and little about her inner world. However, during this situation, she is silent for an extended period of time, which, along with her choice of words, seems to reflect her despair. Jennifer was told several times not to talk about trauma, this is distinctive for this theme in Jennifer's interview. During the interview, the focus is not on this theme. Jennifer has not been able to process her trauma, while she narrated that she wanted to work on her traumatic experiences. Jennifer was refused for trauma-informed care: "There was this belief that people who are psychotic could not process trauma. They were afraid that these people would become psychotic again". She has experienced this as distressing: "That is bizarre. One is going through something hurtful, and everyone is telling one to not talk about it". Jennifer reflected that she wanted care for her trauma. However, there was a fear from professionals that processing trauma would lead to a new psychosis and care was therefore refused. Jennifer was looking for a place where she was able to discuss her trauma, however, this refusal from mental healthcare confirmed Jennifer's feeling that her trauma should not be discussed. As a result, Jennifer did not receive the care she was seeking.

### *Self-sought care*

In Jennifer's interview, the theme of self-sought care appeared in one situation in her life, which she talks about at various points in the interview. Jennifer mainly describes her experience with her self-sought care and also reflects her inner world. This is also distinctive of Jennifer's experience with this care, in which she describes which aspects contribute to her positive experience. This theme is a key focus in her interview. Jennifer is receiving care, brainspotting<sup>1</sup>. Jennifer has been looking for this therapist herself. This therapist can provide Jennifer with what she needs in therapy. The therapist gives Jennifer space and time to pay attention to what Jennifer wants to pay attention to. Jennifer described: "She gives me a chance. We talk for about half an hour about what happened in the past. We choose a topic and start brainspotting ... We can take our time, see what I am feeling and process these feelings". After being refused trauma-informed care, Jennifer sought care herself. It seems that she sought for a place where she was able to discuss her trauma and was no longer ignored. Jennifer seems to have found this place with the help of brainspotting, which she appears to experience as helpful.

### *Humaneness*

In Jennifer's interview, the theme humaneness came to the fore in the current phase in her life, where she talks about the current care she is receiving. During this theme, Jennifer described her experiences. This is also characteristic of Jennifer's theme. This theme is a key focus in her interview. With her current therapist, Jennifer seems to feel seen and heard as a person. Jennifer narrated: "I have the feeling that I can continue with the help of this therapy". However, it seems that she did not feel seen and heard during previous care from mental healthcare as she felt "ignored" since little attention was paid to her traumatic experiences. She therefore missed that mental healthcare looked at her as a person. This gives the impression that being listened to and being seen is what Jennifer was looking for and did not get from mental healthcare, but now receives during her current trauma-informed care. This seems to be an important factor in why Jennifer perceives her current care as helpful.

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<sup>1</sup> A type of alternative therapy that reveals a patient's unprocessed traumas through fixed eye positions (Corrigan et al., 2015).

**“John”: “If this is what [regular] mental healthcare has to offer, I will figure it out myself”**

John is a man in his forties. John is diagnosed with an unspecified psychotic disorder. He has had two psychotic episodes, of which one episode led to a two-week admission into a psychiatric hospital. During his first psychosis, John was prescribed medication. He was not taking any medication at the time of the interview. Furthermore, John has experienced several traumas. Based on these experiences and his symptoms, John was diagnosed with PTSD. John has received regular mental health care practices for both psychosis and trauma. He is currently not receiving care from mental healthcare. John has completed a university education.

John said that he wanted to share his story about disruption and recovery, in which he indicated that what has happened in his life has led to psychoses and PTSD. John has experienced traumatic events in the relationship with his aunt and uncle:

My aunt and uncle could not have children and they treated me as a surrogate child. They fooled my parents. This was a fierce loyalty conflict, in which negative stories went back and forth. My aunt and uncle did eventually have a child. But a few years later they wanted another child and they wanted me as a donor. Nobody was allowed to know. I was in a position where I could not say no. Later there was another incestuous incident. That was also swept under the rug.

However, mental healthcare only focused on the symptoms of psychosis through medication. That is why John went looking for trauma-informed care himself.

During his interview, John comes across as a resilient and optimistic person. After his psychoses he explained he got to know himself and his limits. He knows how to guard his limits and what he can use to prevent psychoses from happening. In addition, he follows training to become an experience expert in order to offer care to individuals with sensitivity to psychosis who also struggle.

***Ignored trauma***

In John’s interview, the theme of ignored trauma came to the fore in one situation, where he factually explains the situation with his psychiatrist. Despite John factually describing the situation, his frustration seems to shine through, partly because John laughed at one point while telling this situation. Characteristic of John’s way of experiencing trauma is

that his psychiatrist states that he is aware of John's trauma but has still ignored it, which seems to be mainly causing John's anger. This theme appears as additional information in John's interview. John researched trauma and he presented his information to his psychiatrist:

Because I had experienced a series of traumatic experiences, which caused a lot of effects, I did research myself. I also presented that to him. And then his response was; oh yes, yes yes. Well, he knew all that. I wondered why he did not do something with that. He is making money off people's backs here. So that really made me angry.

John described that the contact became annoying after this: "I thought okay we are done here. The psychiatrist just needed to write a diagnosis. We arranged that and then I said goodbye to him. If this is what mental health has to offer, then screw you". The psychiatrist diagnosed John with PTSD. He added to his story: "I did not get the care I expected or hoped for". Therefore, after John shared his accumulated information about trauma with a professional, John got the response that the professional already knew this. This gives the impression that John's trauma has been ignored, while it seems that John was looking for acknowledgment of his trauma but did not receive this.

### *Desire to understand oneself*

The theme desire to understand oneself appeared in different meanings in John's interview, which explains his reasons for his desire. John factually talks about how this desire was not fulfilled in mental healthcare. Characteristic of John's way of experiencing this desire is that he narrated a clear picture in which he would understand more about himself through diagnostics in mental healthcare. This theme came forward as additional information in John's interview. At the beginning, John was hopeful to get care from mental healthcare as he had the desire to understand himself: "I was willing to participate in diagnostics. Of course, I also had hundreds of questions, such as what is wrong with me, why is it escalating like this, why am I reacting to certain things". John went into treatment with a psychiatrist for medication. John had appointments with his psychiatrist every two weeks to check the progress of the medication. Then John got another psychiatrist, to whom John asked what was going to happen: "The psychiatrist did not do anything with diagnostics, did not use a treatment plan, he did not find that interesting at all". John continued: "Professionals are looking at you like these are all delusions. Their focus is on symptoms, instead of just starting the conversation". Hence, John was looking for potential causes for his symptoms to be able to fulfil his need to understand

himself and his symptoms. However, in mental healthcare potential causes were not looked at. John experienced that there was only a focus on symptom control. As a result, John did not receive what he was seeking.

### *Own research into recovery*

In John's interview, the theme own research into recovery appeared in a phase in his life, of which he explained his research and helpful information in his interview. John has, among other things, looked up information about biological causes and stated that this was the most helpful for him, which is distinctive of John's way of experiencing his own research into recovery. This theme is not a key focus in his interview. He narrated about his research: "After four years I was done with it, because it was no longer useful to me. In the meantime, I had done a lot of research myself. Neurobiological processes and what happens". So, he came down to trauma as a cause of psychosis after recognizing himself in trauma and the effects it produces. John indicated that he has given himself psychoeducation about this, which has helped him: "To understand that such long-term stress causes damage to your brain. That was enlightening for me". Mental healthcare could not satisfy John's need to understand himself. Therefore, he tried to satisfy this need himself, which he seems to experience as helpful.

### *Self-sought care*

The theme self-sought care came forward in multiple situations in John's interview, in which he briefly explains what care he has sought and for what reason. John tells little about his experiences with this self-sought care, except about his study. About this study, John gives more information about his inner world. Characteristic of John's experiences with this theme is that John has sought care in various ways, all of which seem to contribute to his recovery. This theme is a key focus in John's interview. John explained the care he sought himself after he said goodbye to his psychiatrist:

I sought other care myself. First with a psychologist. EMDR was in development at the time. I did haptotherapy<sup>2</sup>, just to feel safe in my own body again. Bio-resonance therapy<sup>3</sup>... So, I have tried all sorts of things. Well, it slowly went back to normal.

John has also delved into his own trauma. His trauma is about the relationship between his parents, uncle and aunt: “I also thought like I am really going to change course, because this is not going to happen to me again. Then the family story came up again, which I thought of I am going to look into this”. John also conducted research into the experience expertise study because he was aware of the steps he has taken in recovery. He wanted to do more with this and started following that study: “It has given me so much. There was an atmosphere where I felt safe for the first time. In the group in which you could tell your story, where others do too. There is no risk that you will get another pill or another diagnosis or classification”. After John did not get what he was looking for, he started looking for care himself. The care John received appears to be alternative forms of care that take into account the mind-body relationship, which gave him the possibility to reflect on his trauma. Based on the interview, these types of care seem to be helpful to John. Furthermore, John gave the impression he feels the need to further develop his recovery. This need has made John experience the opportunity to share his story without consequences, which seems important to him. This appears to be helpful.

**“David”: “Mental healthcare did not offer much, just medication in fact”**

David is a man in his forties, who is diagnosed with a schizoaffective psychotic disorder. The first time David experienced psychosis, he was extremely scared: “I did not know what was happening to me”. David has been admitted to a psychiatric hospital seven times. The first admission was a forced admission. This admission lasted a year. Since his first admission, David has been using medication for his psychosis. David has experienced several traumas. David has not been diagnosed with PTSD. He has not received regular care practices for his trauma from mental healthcare, only care from his psychiatrist for controlling his medication for his psychosis.

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<sup>2</sup> An alternative type of therapy that involves the use of touch to achieve mental relaxation, as well as interventions such as counselling, to assist individuals in getting in touch with their feelings (Klabbers et al., 2019).

<sup>3</sup> An alternative type of therapy that helps the body to reduce its stress load and to restore self-regulation, using the biophysics of the body (Muresan et al., 2022).

David said that the story he wanted to share was about his process regarding his psychoses. He narrated: “When I was young, I was doing well. At a certain point, several things fell away and then I became psychotic”. He ended up in a psychiatric clinic through a forced admission. After that he lived in a residential form, but it never really went well according to David. He has gone through several traumatic experiences in his life, from which David has suffered a lot. He said: "I lost my father at an early age, because of a divorce between my parents. My father was then expelled from the country”. David continued: “When I was X years old, my mother died in a mental health facility. She had a tumour, but doctors thought she was psychotic. She was admitted and died without treatment for her tumour. ... And I experienced a car accident". From mental healthcare David was not given much, only medication to keep the psychosis under control. That is why he himself sought other forms of trauma-informed care.

Like the other participants, David came across as a resilient and positive person. David has experienced several psychoses which made him very scared. Nevertheless, David managed to focus his life on the positive. David is engaged in many different forms of care: “I am more positive, my emotions are more stable, and I do not have any weird ideas anymore”. He is positive about the future. However, this does not mean that David does not experience difficulties. He is permanently not able to work, which means that David has no job. This gives him the idea that he does not fully function in society. He narrated he is having a tough time to accept this.

### ***Ignored trauma***

In David’s interview, the theme ignored trauma came to the fore in multiple meanings, where he discussed his previous expectations and the consequences of failing to fulfil those expectations. When David discussed this theme in his interview, he fell several silences, which came across as disappointed. This is also characteristic of the way David experiences this theme, stating that he has lost a period as a result of this theme. This theme is therefore a key focus in his interview. David has several traumatic experiences that have not been given attention from mental healthcare. He talked about the care from mental healthcare he received: “They did not give me that much, just the medication in fact. But I think it takes more to have a good life than just the medication”. David therefore experienced a focus on medication from the mental healthcare sector: “Nowadays they mainly focus on the medication. I see it in myself



and many other people that that medication is not the cure-all. It does somewhat help to keep you out of an extreme decompensation, but I still quite lost”. According to David, mental healthcare paid no attention to potential causes and other forms of care. David’s traumas reappeared during psychoses. David experienced that the emergency services did not pay attention to this, and nothing was done about it. So, he has not received care for his traumas. David finds this form of care a pity: “I had hoped that the care would be more intensive. That they would also do things with me, so that I could quickly return to society and not spend years in psychiatry. Now I have lost a lot of years”. Despite the trauma reappearing during his psychoses, David's trauma was ignored. This ensured that he did not receive trauma-informed care. Based on his interview, it seems that David feels like he has not been seen for years, which resulted in the persistence of his complaints. The consequences of this appears to make David feel as if he has lost multiple years of his life. David seems to be upset about this.

### *Self-sought care*

The theme self-sought care came forward as a phase in David’s life, based on his interview. In his interview, David talks about the different forms of care he has sought and what positive consequences this has for him. David has found care with a particular emphasis on mindfulness that he finds helpful, which is distinctive of David's theme of self-sought care. In this he shows little of his inner world. This theme is an important focus for his interview. So, David is working with alternative forms of care, looking at what happened to him and what is currently happening to him now from different perspectives. David came into contact with someone who pointed him to meditation and put him in touch with a life coach. David follows online courses from his life coach, about meditation, yoga, and emotional freedom technique (EFT)<sup>4</sup>. David talked about what these forms of alternative care have brought him: “Since this care, things have gotten better, delusions are now gone because of those methods of medication, yoga, and EFT. ... I am more positive, and my emotions are more stable. I do not feel so lonely anymore”. Furthermore, David has written comics about the unpleasant events in his youth: “I wanted to write that off me, what went through me. I was actually also trained as an illustrator. Now I also occasionally draw comics to process things from the past”. So, after David was not offered trauma-informed care from mental healthcare, he started looking for care himself. He

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<sup>4</sup> A treatment for physical pain and emotional distress, which believes that tapping the body can create a balance in your energy system and treat pain (Clond, 2016).

came to alternative forms of care in which he seems to experience room to process his trauma with the help of the relationship between mind and body, as well as processing in a creative way. Based on the interview, it appears that David perceives this care as helpful. David sought this care for his trauma, but it has also ensured that he no longer experiences symptoms of his psychoses. It appears that this has led to better mental health.

**“Susan”: “Trauma underlies the beliefs I had in my psychoses”**

The last participant is Susan, a woman in her fifties. Susan is diagnosed with a schizoaffective psychotic disorder. She has been admitted into a psychiatric hospital six times. During her first psychosis, Susan was prescribed medication, and she was still taking medication at the time of the interview. Furthermore, Susan has experienced traumatic events, including her admission. Susan has not been diagnosed with PTSD. Susan has received regular care in mental healthcare for both her psychosis and some of the traumatic events. She is currently receiving care from mental healthcare. Susan has completed a university education.

Susan said she wanted to share her story about how she ended up in psychiatry. She narrated that it started with a burnout: “I had a turbulent childhood, often feeling unhappy. There was a lot of quarrelling in my family. I pushed the limits and experimented a lot with alcohol, drugs and boys”. Susan continued: “When I was X years old, I was almost strangled by a homeless person when I was on vacation alone”. In addition, Susan said: “A friend was also psychotic and she committed suicide. Furthermore, my mother got cancer and later committed euthanasia”. This made Susan think she was in a euthanasia ward during her admission. Susan experienced this as “traumatic”. Susan has also developed a fear of small spaces because the isolation cell has had a lot of impact on her. Mental healthcare has not paid attention to her traumas for a long time, so Susan has started looking for trauma-informed care herself.

Throughout the interview, Susan came across as a resilient and strong person. She can articulate well what she has missed in mental healthcare. For this reason, she has become an experience expert in order to help others with her experiences. Moreover, she is aware of the steps she could take to promote her recovery. She sees possibilities again. However, she still runs into her own low self-esteem, but she said that self-esteem is starting to come back.

### *Ignored trauma*

In Susan's interview, the theme ignored trauma appeared in only one meaning, in which she briefly discusses the reason for ignoring the trauma. She does not talk much information about the ignorance of trauma and her experiences with it. This is also what characterizes Susan's theme. What is distinctive of her experience of ignoring trauma is that Susan notices that there is a difference between in-patient and out-patient care. Unlike the other interviews, this theme does not play a key role in Susan's interview. She narrated about the lack of attention to her traumatic experiences: "There were no psychologists in those teams. A psychiatrist was for the medical part and a psychologist for healthy people with a problem. I am glad that is changing a bit now". Therefore, Susan indicated that there was a different approach to care for admitted individuals compared to individuals who received outpatient care. Accordingly, there was no room for Susan to work on problems other than those for which she was admitted into a psychiatric hospital, which resulted in the ignorance of her trauma.

### *Self-sought care*

The theme self-sought care of Susan appeared in different situations, in which she explained the types of care and the reasons why she has chosen this care. Susan spoke little about the helpful aspects of the care in these situations. Characteristic of this theme of Susan is that the care for her trauma took many years. This theme is a key focus in her interview. Susan has already started processing her traumatic experiences but is currently also working on it. Susan has already had EMDR therapy at various traumatic events in her life. This has helped her a lot. However, she has not yet received care for her traumatic experience in the isolation cell. Susan will soon receive schema therapy for this. However, Susan would also like to use EMDR therapy on this experience: "I would also like to add EMDR therapy to that. I have actually only had monitoring contacts because of my admissions. But no treatment yet for the consequences. But that is finally going to happen after 23 years in psychiatry". Susan herself was able to partially process her traumatic experiences in the isolation cell through creativity: "I believe that creativity is healing. I did a writing workshop at the client council. There we learned to write and made a booklet with our isolation experiences. Then I was able to give it a bit of a place". As a result of ignoring the trauma, Susan has not been offered any care for this. That is why she went looking for trauma-informed care herself. That is how she ended up with

EMDR therapy. It appears that Susan has experienced this form of care as helpful and would therefore like to use it for the remaining trauma. In addition, Susan herself has started to process her trauma with the help of creativity. What seems to have been helpful in this is that Susan had a place to reflect on her trauma. However, ignoring her trauma has left her with symptoms of trauma for 23 years.

### ***Humaneness***

In Susan's interview, the theme humaneness came to the fore in different meanings, where she talks about the aspects that she has missed in previous care. In contrast to her previous themes, Susan shows more of her inner world during this theme. Characteristic of this theme of Susan is that she already missed this during her previous care and therefore actively looked for care in which she could find humaneness. This theme is therefore also an important focus in her interview. Throughout the interview, this aspect is discussed multiple times. Susan has missed contact from the professionals for a long time in mental healthcare in general, in both the admissions and the care of psychosis and trauma. She has noticed that she has often been approached out of fear by professionals, of which she actually said: "It is not necessary. We are afraid enough ourselves". Susan narrated that she wants to be approached as a person, where she values humanity in the contact. Susan said: "I want to be seen as a normal person. There is always a healthy bit left. There is always something that just wants to get better". As an example where Susan has experienced humaneness, she talked about an admission that she experienced more pleasantly than her first admission because of humanity: "I was isolated, but that this one in consultation. When I pressed the bell, someone came. When I went to take a shower, someone came to me instead of me having to shower alone". Consultation and contact was important to her: "There was someone standing next to me and there was consultation. That you just feel the consultation and contact. So, I trusted them". Susan gives the impression that being seen as a normal person with autonomy and being respected is important for her experience in care, as well as for her recovery.

### **Discussion**

The aim of this study was to get a better understanding of the kind of trauma-informed care individuals with sensitivity to psychosis seek and receive, and how they perceive this care.

Based on the expressed experiences of the participants, trauma in psychosis is often ignored and undertreated in mental healthcare. Participants reported that mental healthcare often did not pay attention to trauma. When trauma was acknowledged, participants were often refused trauma-informed care by mental healthcare out of fear for a new psychosis. This indicates that the participants of this study experienced that they were not receiving trauma-informed care from mental healthcare they were looking for. As a result, the participants have done their own research into trauma in psychoses and the possibilities for trauma-informed care. Their own research plausibly helped the participants to recognize their specific needs with regard to trauma-informed care. Participants sought for various types of trauma-informed care themselves. With this self-sought care, within or outside mainstream psychotherapy, the participants experienced the possibility to reflect on their trauma and felt as if they were taken seriously. Consequently, the participants received what they are looking for in their trauma-informed care and are satisfied with this care.

One important way in which trauma matters in psychosis is that, according to the participants of this study, trauma surfaced during a psychosis. A re-experience of a prior trauma was triggered by and part of the psychotic episode. However, their trauma was not located during psychosis as the participants experienced that mental healthcare often paid no attention to the participants' trauma, which corresponds with research of Read et al. (2017). In line with previous research (Wood et al., 2019), the participants experienced that mental healthcare was aimed at symptom control with regard to their psychosis, and that therefore no attention was paid to underlying causes, such as trauma. Given the role of trauma in psychosis, it is important to explicitly use trauma-informed care instead of ignoring trauma since ignoring hinders recovery from both trauma and psychosis, according to the participants. Grubaugh et al. (2011) indicated that a plausible reason for not locating trauma during psychosis could be that there are concerns that individuals with sensitivity to psychosis may not be able to accurately report on their traumatic memories and associated symptoms, due to the nature of psychotic disorders. However, their research has shown that these individuals are capable of reporting their trauma. Moreover, the current study adds insight into how participants perceive their ignored trauma. The narratives demonstrate that the participants felt misunderstood and not seen, which made them disappointed in the care. This study, together with previous literature, emphasizes the relevance to make the fundamental shift of trauma-informed care with moving from thinking 'What is wrong with you?' to considering 'What happened to you?' in order to treat both trauma and psychosis in individuals with sensitivity to psychosis.

The participants were keen to receive trauma-informed care for their trauma. In line with research of Hobfoll et al. (1995), the participants were looking for a place where they were able to discuss their trauma and were taken seriously. Unfortunately, the participants experienced refusal of trauma-informed care from mental healthcare, some out of fear for another psychosis, which corresponds with the study of Van den Berg et al. (2016a). Their findings indicated that some practitioners believe that trauma-informed care will destabilize individuals with sensitivity to psychosis and worsen symptoms. However, the reality is that increase of symptoms in trauma-informed care is rare and, when it does occur, it is often temporary and unrelated to treatment response (Foa et al., 2002). Van den Berg et al. (2016a) found that specialized training, including practical training with supervision, has long-term positive effects on practitioners' harm expectancies concerning trauma-informed care. In addition to previous literature, the current study shows that the participants felt unsupported and developed the idea that trauma should not be discussed as a result of the refusal of trauma-informed care. Along with the knowledge that untreated trauma in individuals with sensitivity to psychosis impede recovery from psychosis (Mueser et al., 2010), it is important to focus on psychological processes underlying psychosis and to treat trauma in order to recover from psychosis. Therefore, it is necessary to increase practitioners' knowledge on trauma-informed care in psychosis with specialized training.

Based on the expressed experiences of the participants, they felt the desire to understand oneself with regard to their psychosis and its causes in order to prevent them, which corresponds to previous research (Hallett et al., 2013). In contrast, the participants of the current study add that they experienced that they were not able to obtain this information from mental healthcare and had to conduct their own research into psychosis and its causes. Moreover, the participants indicated the importance to look at explanations beyond a biological explanation. Research of Department of Health (2010) indicated that providing such information can improve service users' satisfaction and empower these individuals for further participation in their decision-making process, which may result in better clinical outcomes and higher quality of life. However, research on information need among individuals with mental disorders is limited. Therefore, further research is needed to collect data about the information need among individuals with mental disorders, including individuals with sensitivity to psychosis. Future research will therefore have to specify what individuals want to know and in which way this information can be best conveyed. In addition, this narrative study shows that the participants did their own research into recovery after refusal of care. They investigated multiple possible

explanations in order to increase the trauma-informed care options and to generate hope for recovery. Therefore, it seems important for professionals to look beyond biological explanations in order to transfer this knowledge to individuals with sensitivity to psychosis and to be able to offer these individuals appropriate care.

The kind of trauma-informed care the participants sought themselves was quite varied. Some participants looked for trauma-informed care within mainstream psychotherapy, for a place where they can reflect on their trauma and feel trust and respect. In line with previous research (Van den Berg et al., 2016b), some participants consciously sought for EMDR as trauma-informed care, of which they narrated as helpful. Other participants sought alternative types of care, taking into account the relationship between their body and mind, or forms of mindfulness. This study showed that they experience these forms of care as effective, which is in line with previous research that shows that care that pays attention to the relationship between mind, brain, and body (Wilkinson, 2017) and mindfulness (Follette et al., 2006) is effective. Some participants sought creative forms of care, which they experienced as effective. This is in line with previous research, which indicates that individuals who have experienced trauma can benefit from creative forms of care (Körlin et al., 2009). However, not every form of alternative care the participants sought were trauma informed. Not all alternative care providers seem to be experts on the relationship between trauma and psychosis, yet this does not seem to be essential since the participants still experience these forms of care as effective. An important factor for its effectiveness seems to be that the participants were taken seriously, as opposed to previous regular psychotherapy. This reflects the importance for care professionals, both regular and alternative care, to take the individual seriously. However, the previous studies about the effectiveness of these forms of care are not aimed at individuals with sensitivity to psychosis. Little to no research has been conducted into the effectiveness of these forms of care for these individuals. An explanation for this could be that this target group is often excluded from research (Mueser et al., 2002; Van den Berg et al., 2016a). Although the results of the current study may be a first step, it is necessary that future research focus on the effectiveness of these forms of trauma-informed care for specifically individuals with sensitivity to psychosis.

The different forms of care the participants ended up with might be explained by the experiences or beliefs of the participants as expressed in their stories. Some participants sought for EMDR therapy because they experienced that this form of care is effective in processing previous trauma. A few participants experienced their trauma symptoms in their bodies and looked for alternative forms of care that involved the relationship between mind and body,

whereas other participants used alternative forms because they wanted to look from different perspectives. Another participant sought for alternative care where she felt she was able to talk about her trauma, as she had previously experienced not being able to talk about trauma for a longer period of time. Other participants used creative forms of care as they experienced before that creativity helped them to process emotions. Therefore, individuals seek care based on their needs and preferences. Not every form of trauma-informed care suits every individual. Hence, it is always important to look at the individual and to tailor care accordingly.

Despite the differences in the forms of care, based on the interviews, it can be concluded that the participants were looking for a place where they could reflect on their trauma and would be taken seriously. They wanted to experience autonomy within their care. Therefore, what the participants were actually looking for was mutual trust, respect and shared decision making, or a good therapeutic relationship (Farrelly & Lester, 2014). They have not found this in regular mental healthcare, which is in line with findings of Farrelly et al. (2015). However, with their self-sought care, the participants experience a good therapeutic relationship, which seems an important factor of why their self-sought care is perceived as effective. This corresponds with previous research that has shown that a therapeutic relationship is associated with improved outcomes of individuals with sensitivity to psychosis (Farrelly et al., 2014). As an addition to previous literature, this narrative study suggests that relational care might be more important for individuals with sensitivity to psychosis than specific evidence-based interventions for trauma. In order for professionals to ensure relational care, they should gain knowledge to effectively assess and treat trauma (Walters et al., 2015). However, it is critical that professionals are not only trained in asking sensitively about traumatic experiences, but also in how to best respond to disclosure and how to translate the information into meaningful individualised services. Furthermore, professionals should understand coping adaptations (Sweeney et al., 2018). In shifting to a trauma-informed model, professionals should better understand behaviours that enable an individual to cope in the present moment. Whether or not professionals see it as symptoms of an underlying disorder or as coping, their response to it can either cause more distress and heighten alarm or can support a lessening of distress.

The interviews do not specify what kind of trauma-informed care the participants were looking for primarily from mental healthcare. In addition, it is not always clear from the interviews what was specifically useful about the care the participants sought themselves. The reason for this is that an already existing dataset was analysed for this study. These interviews were therefore not specifically focused on the topic of this study. As a result, the interviews



occasionally lack relevant details for this study, and this is therefore a limitation of this study. At the same time, an existing dataset is a strength of this study as it ensures that more participants have been reached than the researcher could reach herself, especially with the selection criteria of this target group. Because this study does not clarify these details, future narrative research should focus on the relevant details that this study lacked. Future research should therefore investigate what kind of trauma-informed care individuals with sensitivity to psychosis are looking for within mental healthcare, but also what was specifically useful about the care participants of this study sought.

All participants started looking for care themselves, which might be explained by the sample of this study as all participants appear resilient in their narrative. An explanation for participants who seem resilient is that, according to Herrman et al. (2011), individuals who are resilient look for positive adaptation to regain mental health despite experiencing adversity. Hence, the participants who appear resilient seek solutions for trauma-informed care after disappointments. Since seeking trauma-informed care was an inclusion criterion for this study, it may be that less resilient individuals have been filtered out for that reason as a result. Another explanation could be that individuals who appear resilient may have a greater need or more energy to share their story than individuals who are still stuck in their setbacks within mental healthcare. It may also be that individuals who seem resilient are able or ready to talk about trauma, whereas individuals who seem less resilient are unable or not ready to share their story. These reasons may also explain why this sample consists of only five interviews. The fact that this sample consists of only five participants is therefore a limitation of this study. This means that the results should be interpreted with caution. However, this does not mean that individuals with sensitivity to psychosis who appear less resilient do not experience refusal of trauma-informed care or undertreatment of trauma. Future narrative research should therefore focus on the experiences of treatment of this group. This study, however, shows that there is a small group that can serve as spokespersons for something that is a common phenomenon, only a few individuals make the effort or are able to share it. This has provided a valuable insight. Little qualitative research has been done on this sample, which makes this a strength of this study.

## **Conclusion**

This study provides a better understanding of what individuals with sensitivity to psychosis seek in trauma-informed care and which care they receive, but also how this is

perceived. Using a narrative approach, insight is given into the experiences of trauma-informed care of this underrepresented group. This could complement the few qualitative studies about individuals with sensitivity to psychosis. This study has pointed out that relational care might be more important than evidence-based treatment. Taken together the results of this study and previous research, it can be concluded that it is crucial for professionals to also focus on psychological processes underlying psychosis and to diagnose and treat trauma in individuals who are sensitive to psychosis, with more attention to the therapeutic relationship in order to positively affect treatment outcomes. In alignment with previous studies, it is important for professionals to encourage open conversation, listen and understand the individual, and to engage their social network, in order to make the fundamental shift in providing support using a trauma-informed approach to consider what has happened to the individual

There are some directions for future research on trauma in individuals with sensitivity to psychosis. Future research should investigate what kind of trauma-informed care these individuals are looking for within mental healthcare, but also what was specifically useful about the care participants of this study sought. Furthermore, more research is needed on differential experiences and effects of trauma-informed psychosis care depending on how resilient individuals are. However, this study provides insights that could be used in future research to bridge the gap in current literature and consequently provide better trauma-informed care for individuals with sensitivity to psychosis.

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