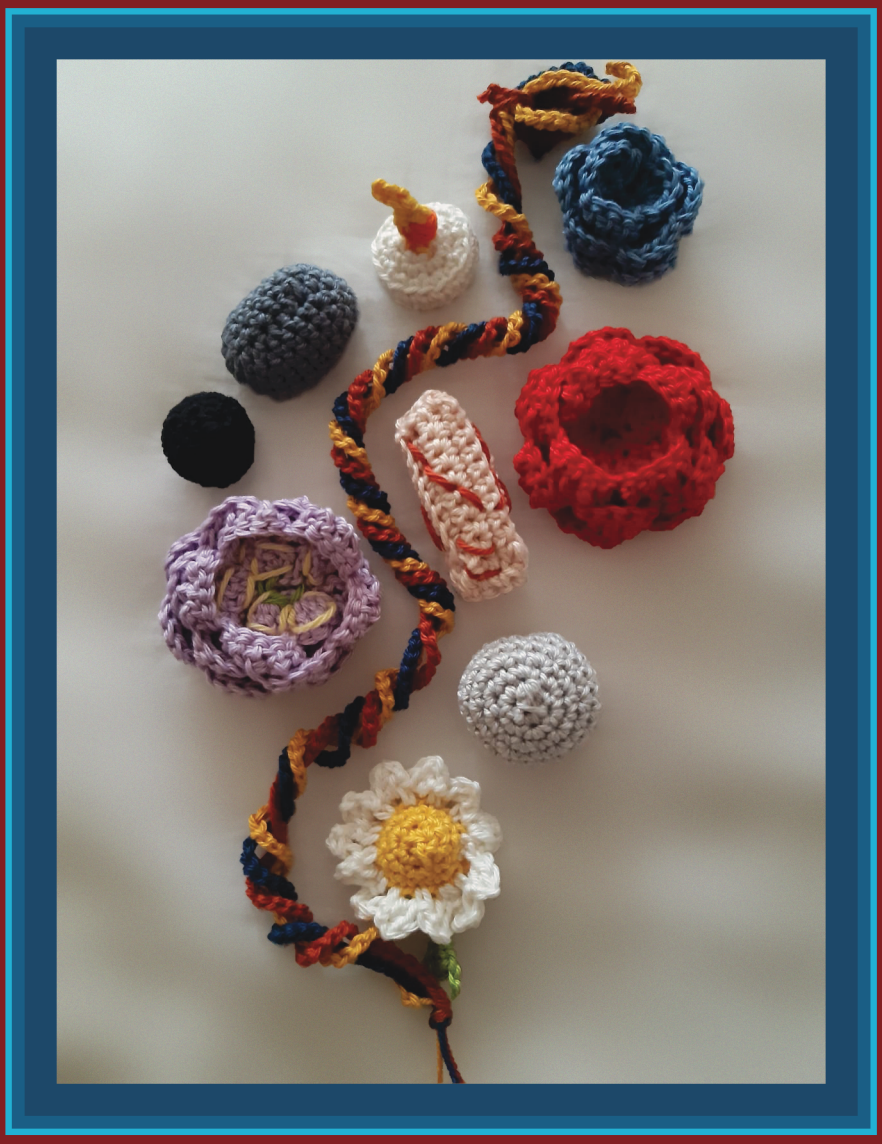
TRAUMATIC LIVES FINALLY LIBERATED

NARRATIVE EXPOSURE THERAPY IN PATIENTS WITH SEVERE MENTAL ILLNESS



MARIA MAURITZ

Traumatic lives finally liberated

Narrative exposure therapy in patients with severe mental illness

Maria Mauritz

2023

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Promotoren:

Prof. dr. H. Vermeulen

Prof. dr. P.J.J. Goossens (Universiteit Gent, België)

Copromotor:

Dr. H.G.I. van Gaal

Manuscriptcommissie:

Prof. dr. A.E.M. Speckens

Prof. dr. N. Boonstra (Universiteit Utrecht)

Prof. dr. B. van Meijel (Vrije Universiteit Amsterdam)

CONTENTS

“Come forth tonight with stories… every time I will weep”

Leo Vroman, De Gids, 1954

Chapter 1

General Introduction

"Stories from the past, shape the present…"

My grandfather was a born storyteller. Born in 1912 and raised in Huizen at the Dutch Zuiderzee, his exciting stories at family gatherings kept his numerous grandchildren completely silent. He spoke in his Saxon dialect which we understood well, but no longer spoke ourselves.

He had many different stories. For instance, as a boy he had to lay a hold of a new catch of fish by calling it "mine" at the fish auction at the harbour. He proudly told how well he did this for his father. He also told us about the loss of his first born baby boy. There were several stories of another kind, such as the damming and reclamation of the Zuiderzee and its consequences for the fish stocks. And about the Second World War, when he went to Kampen with his brothers to get food during what is called the hunger winter and how his faith prevented them from ending up in a raid.

The saddest story he only told in small circles. At the age of sixteen, he saw a crowd gathering at the harbour. Getting closer, folks were reanimating a swimmer taken out of the water. It was his 2-year older brother Marcus, who died before his eyes. Before this tragic loss, his father played the accordion, but after the accident, he never played the accordion again.

Forty-eight years later, when I was ten years old, he also lost his younger beloved brother, Peter.
Peter was often depressed and treatment had little effect. In a bad period, he often told my grandfather: "Marcus is calling me"… One day he disappeared and couldn't be found. My grandfather presumed he had gone to the harbour. After a whole day searching and dredging in the foggy harbour, he witnessed his brother taken out the water, drowned. At home, my grandfather cried out loud and his deep mourning has always stayed with me.

Back then, the concept of trauma was hardly known. Nowadays, it is clear how traumatic these losses were. The impressive stories of my grandfather have shaped me and inspired me to become a psychiatric nurse. They made me aware of the impact on humans of traumatic events and explained my search for the stories in people, especially severe mentally ill patients.

My first nursing job consisted of taking care of schizophrenia patients in a psychiatric hospital. These patients were mainly young men who had perceived a lot of loss. At the time, little attention was paid to these experiences and its meaning. A few years later during nursing science training, loss and grief in schizophrenia became my first scientific topic. During my second job in a University Medical Centre in the nineties, the existence of trauma and the need for effective trauma focused treatment was increasingly recognized in clinical practice. Cognitive Behaviour Therapy (CBT) and Prolonged Exposure were the first treatments performed.

Clinical experiences with psychotrauma and posttraumatic stress disorder

From 2004 to 2011, my role was to lead a Support & Psychosis team which was part of GGNet, a large mental health institution in the east of the Netherlands. This position included team management with providing nursing care and psychosocial support to outpatients with psychotic and other severe mental disorders. Our team was enthusiastic and provided good care and guidance. However, the patients' treatment mainly consisted of prescribing medication, but cognitive and psychotherapeutic interventions were not performed at the time.
During the multidisciplinary team consultation, we noticed that the involved psychiatric nurses often mentioned that their patients had a history of abuse and neglect. However, these traumatic events and their consequences were not further discussed with the involved patients, and team members.

The result was that the information on abuse and neglect wasn't accessible in a central place in the patient's records. Clinical literature showed that the lifetime exposure to trauma and Posttraumatic Stress Disorder (PTSD) in severe mental illness was very high, but was often not mentioned in patients' records [1-3].

At that time, the team did not have psychologists involved that could treat PTSD or other comorbid disorders because the view was that psychological interventions were not effective, or even harmful in patients with severe mental illness (SMI) because they were considered as too vulnerable. This belief was widely shared by mental health practitioners, but unsubstantiated.

The first randomized trial about trauma and PTSD in SMI patients was published in 2008 and compared CBT with treatment of usual in with comorbid PTSD. The findings suggested that SMI patients with comorbid PTSD can benefit from CBT, despite severe symptoms, suicidal thinking, psychosis, and vulnerability to hospitalizations [4].

Thus, our team was confronted with patients who suffered from SMI and undiagnosed PTSD, while at the same time we missed effective treatment modalities and competences to treat the PTSD in these vulnerable patients. This triggered the question how many of our patients with psychotic, bipolar, depressive, or borderline personality disorders indeed suffered from traumatic events. And how this was intertwined with their main disorder, and what therapies would be available to alleviate their suffering of PTSD. To answer these clinical questions, in 2011 we started this research project at GGNet in collaboration with Radboudumc.

At this time, we improved the clinical practice by training team members in stabilizing interventions based on the treatment manual [5] and the Trauma Screening Questionnaire (TSQ) aimed to recognizing trauma and PTSD [6].

Vignette

Patient H. is a 53-year-old man who was diagnosed with Bipolar Disorder type I at the age of 22. The social psychiatric nurse, who has been accompanying him for a long time, suspects that he has been traumatized in the past. H. told her that in his youth he was often bullied and beaten by his father. The nurse discussed this information with the multidisciplinary team. The advice was to do a diagnostic structured interview focused on trauma and Posttraumatic Stress Disorder (PTSD) by a trained Nurse Practitioner. The results showed that from the age of five to sixteen, there was repeated emotional and physical violence by his father. From the age of 25, he started having bad, terrifying memories and nightmares. During manic and psychotic episodes, these memories got worse, but he didn't dare to share these experiences until now. Based on structured diagnostics the diagnosis of PTSD was made.

This vignette describes a case with the important concepts about trauma, PTSD, and Bipolar disorder, which is characterized as SMI in a clinical context.

Relevant concepts

Psychotrauma

The term psychotrauma is literally translated as "an injury to the soul". It refers to a very profound or shocking experience, or to a series of such experiences. The Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) [7], defined psychotrauma as exposure to actual or threatened death, serious injury, or sexual violence in one or more of four ways: (a) directly experiencing the event; (b) witnessing, in person, the event occurring to others; (c) learning that such an event happened to a close family member or friend; and (d) experiencing repeated or extreme exposure to aversive details.

Traumatic reactions occur when action does not benefit the situation. Schauer and Elbert (2010) [8] made this clear and showed the cascade of biological defensive reactions in case of great threat and finally when the victim has no escape. They distinguished six stages: freeze, flight, fight, fright with tonic immobility, flag, and, faint (Figure 1) [8]. This leads in the end to increasing dissociation in which anaesthesia and unconsciousness occurs.

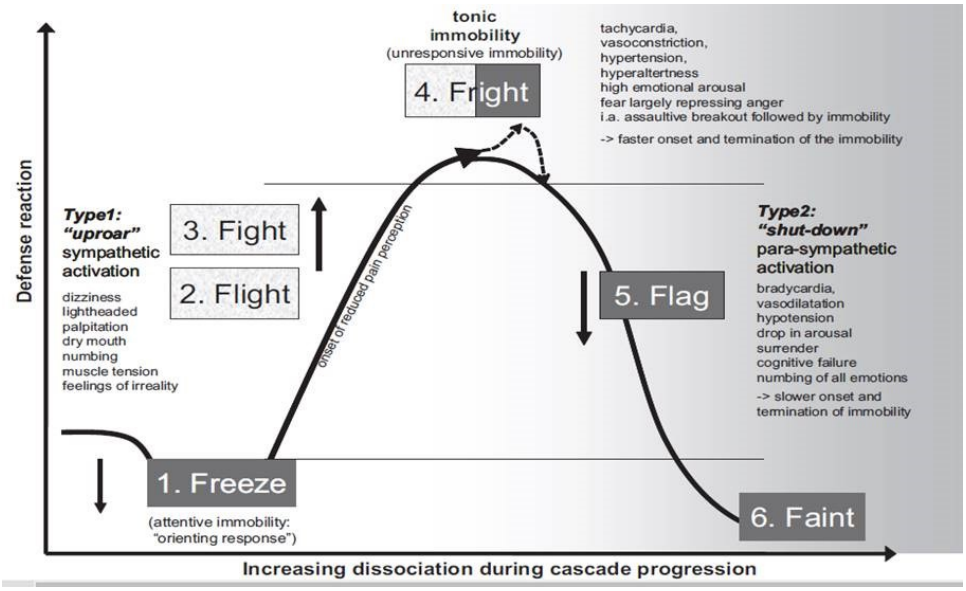

Figure 1. Stages in the biological defence reactions to external threat (Schauer and Elbert, 2010).

If neither resistance nor escape is possible, the human self defence system can no longer handle the threat. During the traumatic event, sensory information is more strongly stored, which leads to re-experiencing of the trauma situation. Psychotrauma causes profound changes in the body's arousal system, emotional life, cognitive ability, flashbacks, and nightmares in the victim. People living with unresolved psychological trauma suffer from a chronic hyper-activation of the autonomic nervous system that produces a constant alertness that can lead to total exhaustion in case triggers that refer to the trauma itself or accompanying emotions arise. Sleep disturbances often occur, because this wakefulness also occurs during sleep [9, 10].

Interpersonal trauma

Interpersonal trauma refers to ”the range of maltreatment, interpersonal violence, abuse, assault, and neglect experiences encountered by children and adolescents, including familial physical, sexual, emotional abuse and incest; community-, peer-, and school-based assault, molestation, and severe bullying; severe physical, medical, and emotional neglect; witnessing domestic violence; as well as the impact of serious and pervasive disruptions in caregiving as a consequence of severe mental illness, substance abuse, criminal involvement, or abrupt separation or traumatic loss” [11]. The short definition involves any of the following traumatic experiences: emotional abuse, emotional neglect, physical abuse, physical neglect, and sexual abuse. These experiences can occur in childhood [12], in adulthood or in both stages of life [13].

Repeated interpersonal trauma has serious consequences, especially in children because they cannot develop safely and are often dependent on the perpetrator(s) such as parents, other family members or significant others. In children, it leads to alterations in attachment and central neurobiological systems, leading to increased responsiveness to stress that increases the risk of psychopathology in both children and adults [14].

Childhood trauma is also a risk for developing severe psychiatric disorders next to PTSD such as: Major Depressive Disorder [15, 16], Bipolar Disorder [17], Psychotic Disorder [17], [18], and [19] Borderline Personality Disorder (BPD). Stumbo et al. (2015) [20] showed that exposure to adverse experiences in SMI patients is high in childhood (91%), adulthood (82%), and lifetime (94%). In this study adverse adult experiences were more important predictors of mental health, physical health, quality of life, social functioning, and recovery than adverse childhood experiences [20].

Posttraumatic Stress Disorder (PTSD)

The Diagnostic and Statistical Manual of mental disorders (DSM-5) classifies PTSD with four symptom categories including (1) intrusive symptoms such as intrusive re-experiences and bad dreams, (2) persistent avoidance, (3) negative changes in cognitions and mood, and (4) changes in arousal (alertness, excitement), wakefulness and reactivity. One of the characteristics of a PTSD is that these symptoms last longer than a month [7]. PTSD symptoms have a major impact on a person's functioning and often also in the person's immediate environment. The DSM-5 further distinguishes two specifications: PTSD with dissociative symptoms (depersonalization and derealisation) and PTSD with delayed expression [7, 21]. The lifetime prevalence for PTSD in the Netherlands is approximately 6.7% (n = 90) to 7.4% (n = 1078) [22, 23]. PTSD occurs worldwide in 5-10% of the population and is twice as common in women as in men [24].

Complex PTSD

The International Classification of Diseases *11th* version (ICD-11) defines Complex PTSD which consisted of the following PTSD symptoms according to: intrusions, avoidance, and increased arousal, and besides these symptoms also complex symptoms: emotional dysregulation, interpersonal problems, and negative self-image. Complex PTSD is suggested as a distinct diagnostic entity [25, 26]. However, there is an ongoing debate whether Complex PTSD is a clearly defined distinct entity or a PTSD with comorbid with BPD. Both conditions share core symptoms, such as affecting dysregulation and self-organization disturbances, but Complex PTSD is defined by a deeply negative sense of self and an avoidant attachment style that are stable and follow complex trauma. This is not described in the diagnostic criteria of BPD [27].

Dissociative Identity Disorder (DID)

A dissociative disorder is a psychological disorder in which dissociation is the most important central feature. Dissociation is a disturbance and interruption in the normal integration of consciousness, memory, emotion, perception, body experience, motor control and behaviour. DID is often seen in the aftermath of childhood psychotrauma and is associated with PTSD [7, 28-30].

Severe Mental Illness

In 1990 the first definition of SMI was provided by the USA National Institute of Mental Health (NIMH): a diagnosis of non-organic psychosis or personality disorder; prolonged illness and long-term treatment; and disability including three of eight criteria: (a) social behaviour demanding a mental health intervention; (b) limited ability to obtain assistance; (c) impaired activities of daily living and basic needs; (d) impaired social functioning; (e) impaired performance in employment or (f) non work (homemaking); (g) vulnerability to stress; and (h) disability that causes dependency ([31]. In the Netherlands, severe mental illness (SMI) refers to a psychiatric disorder that requires care and treatment, accompanied by severe limitations in social functioning. Coordinated care from professional care providers in care networks is indicated in order to realize optimal treatment [32].

SMI consisted mostly of the following disorders: psychotic, bipolar, major depressive, and serious personality disorders with a chronic course. The studies in this thesis focused on these disorders. Other mental disorders can also have a severe course with chronic symptoms, but they are beyond the scope of this thesis.

Trauma focused therapy

Controlled intervention studies have shown that trauma-focused therapy (TFT), such as Prolonged Exposure, Eye Movement Desensitization Reprocessing (EMDR), and cognitive behavioral treatment (CBT) for PTSD are effective in SMI patients [33, 34].

Narrative Exposure Therapy (NET), is an alternative TFT for patients who are exposed to repeated traumatic events during their life cycle. NET integrates prolonged exposure into the life story and includes attention to positive meaningful events. Until now, NET was not provided in SMI patients with a history of repeated traumatic events. Because of the repeated traumatization in this group, NET appears to be an appropriate therapy for this vulnerable group.

Vignet continued

After establishing the PTSD diagnosis, the multidisciplinary team suggested therapy with Eye Movement Desensitization and Reprocessing (EMDR). Patient H. followed this advice. During and after EMDR treatment a well-known psychiatric nurse offered support including stabilizing interventions. The psychiatrist monitored the pharmacotherapy. The Nurse Practitioner carried out the EMDR treatment. After fifteen sessions, the treatment was concluded with good results, with the PTSD being in remission. Bipolar symptoms also decreased: psychotic symptoms were in remission and mood swings became less intense. As a result, medications were reduced to significant lower doses. After more than 18 years living with PTSD, H. says: "I have my life back".

Research aims

The first aim of this thesis was to study the relevance and clinical practice of treating PTSD in SMI patients. This was done by reviewing the prevalence of interpersonal traumatic experiences and PTSD in SMI patients (3.1, Chapter 2), and by a practice-based case study on the treatment of a patient with Complex PTSD using a three-phase treatment modality (3.2, Chapter 3).
The second aim was to evaluate NET as an new emerging treatment for PTSD in SMI patients. To this end a mixed method study was designed (3.3, Chapter 4), consisting of a quantitative strand (3.4, Chapter 5) and a mixed qualitative-quantitative strand (3.5, Chapter 6). The thesis concludes with a general discussion (3.6, Chapter 7).

Prevalence study: a systematic review

In clinical practice, the occurrence of psychotrauma and trauma related disorders in SMI patients has not been an issue for a long time. Traumatic events were occasionally mentioned, but not systematically recorded in patients file. SMI patients were not screened for interpersonal traumatic events in the past and the resent. As a result, the possible presence of PTSD was unknown, let alone treated. Therefore it was important to find out how many SMI patients had been exposed to abuse and neglect with possible current PTSD as a result [35].
The objective was to substantiate the prevalence of interpersonal trauma exposure and trauma-related disorders in people with severe mental illness (i.e., psychotic, bipolar, depressive, and personality disorder). The following three questions were leading: (1) What is the prevalence of emotional, physical, and sexual abuse, as well as emotional and physical neglect. (2) How often do PTSD, Complex PTSD, and dissociative disorders occur in SMI. (3) How may psychotrauma and trauma related disorders influence the main severe disorder: psychotic, bipolar, depressive, and personality disorder. These questions were addressed by means of a systematic literature review (Chapter 2).

Complex PTSD: a case study

In 2010 was the view that therapy for Complex PTSD [9], should be phase based. Judith Herman stated that when a secure healing relationship has been established and safety is ensured, three phases occur: memory and mourning, and recovery and connection [9]. These phases in experienced processing, were used for a therapy model: phase based approached treatment [36, 37].
The female patient in this study was a severely mentally ill case involving Complex PTSD and psychosis related to Dandy Walker Syndrome. She also was very depressed. At that time psychotic patients were hardly treated with exposure. The common view was that patients with psychosis could not tolerate exposure. We started with optimal medication and a phase based approach in this patient. This treatment included (1) stabilization [5, 36, 38], (2) prolonged exposure [39] with intensive support from nurses, and (3) integration of traumatic memories, mourning, and recovery of connection [40]. The objective was to describe and evaluate the therapeutic process of this single case from a holistic perspective (Chapter 3).

Narrative Exposure Therapy for PTSD in SMI: a study protocol

Around 2012 Narrative Exposure Therapy (NET) was introduced in the Netherlands at ARQ Centrum'45 [41]. This treatment was originally designed to target refugees with PTSD who were exposed to repeated traumatic events and living in unstable conditions [42]. At the same time, it was clear in clinical practice, that SMI patients with comorbid PTSD were also often exposed to repeated traumatic experiences. That's why we assumed that especially NET could be an appropriate trauma therapy for

vulnerable SMI patients. Therefore, we developed a study protocol to investigate NET in SMI patients with comorbid PTSD (3.3). The third objective was to evaluate the efficacy and applicability of NET in SMI patients (3.4), and the fourth objective focused on the experiences of SMI patients with NET and the relation with diagnostics results (3.5).

NET is described as follows: 'a short treatment approach that was developed for the treatment of PTSD resulting from organized or family violence'. In NET, the patient repeatedly talks about each traumatic event in detail while re-experiencing the emotions, cognitions, physiology, behavioural, and sensory elements and meaning content associated with this event'. With the guiding of the therapist, patients construct a narration of their life. The focus is on exposure of traumatic experiences and to regain positive events. Because of the chronological order, a sense of coherence, control, and integration is developed [41, 43, 44].

There is evidence for the effectiveness of NET within vulnerable patient groups with repeated interpersonal trauma, but NET has not been given to SMI patients so far. In the Netherlands, SMI patients usually receive Flexible Assertive Community Treatment (FACT) provided by multidisciplinary community mental health teams.

In this study protocol, the primary objective is to evaluate NET in SMI patients with comorbid PTSD who are treated in a FACT-context. To investigate whether**:** a) PTSD and dissociative symptoms would change and b) changes occur in SMI symptoms, care needs, quality of life, global functioning, and care consumption (SMI indicators). The second objective is to gain insight in patients' experiences with NET and to identify influencing factors on treatment results (Chapter 4).

SMI patients receiving NET for PTSD: a single group pre-test-post-test repeated-measures study

Interpersonal trauma and PTSD in SMI patients negatively affect the illness course [35, 45-47]. Treatment of PTSD is therefore important, with the assumption that, if successful, trauma focused treatment may also improve the present severe mental disorder. The evaluation of the course of both PTSD and the actual SMI is important in this.

NET is indicated in PTSD due to multiple and repeated trauma [41]. It is also effective in vulnerable patient groups, but it is until now not been studied in SMI outpatients.

The objective is to evaluate a) the efficacy and applicability of NET in SMI on changes in PTSD, dissociation, and SMI indicators b) on changes in SMI indicators consisting of symptoms, care needs, quality of life, global functioning, and care consumption (Chapter 5).

The efficacy and experiences with NET in SMI patients: a mixed methods design

Next to the quantitative approach which focuses on efficacy based on diagnostic parameters, the question is to know how SMI patients experienced NET treatment and its effect. In-depth interviews therefore are held with each participant in this study. The purpose is to examine the relation between changes in diagnostic outcomes and the experiences of the participants.

The objectives were (1) to evaluate whether NET in SMI outpatients changes PTSD, dissociation, and SMI indicators. (2) To gain insight how patients perceive this therapy. (3) To identify influencing factors on therapy results and to compare diagnostic changes with patient's experiences (Chapter 6).

Conclusion

The general discussion provides a reflection on the main findings with methodological considerations, and directions for research. Furthermore, implications for general mental health and specific nursing practice are discussed, including relevant education (Chapter 7).

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“The family, the community in which children grow up, should be a safe place…

Especially in a family context people make the greatest chance of being mistreated”

Intieme oorlog, over de kwetsbaarheid van familierelaties

Martine Groen & Justine van Lawick, 2008

Chapter 2

Prevalence of interpersonal trauma exposure and trauma-related disorders in severe mental illness: review article

Maria Mauritz

Peter Goossens

Nel Draijer

Theo van Achterberg

European Journal of Psychotraumatology, 2013*, 4,* 19985

ABSTRACT

Background: Interpersonal trauma exposure and trauma-related disorders in people with severe mental illness are often not recognized in clinical practice.

Objective: To substantiate the prevalence of interpersonal trauma exposure and trauma-related disorders in people with severe mental illness.

Methods: We conducted a systematic review of four databases (1980-2010) and then described and analysed 33 studies in terms of primary diagnosis and instruments used to measure trauma exposure and trauma-related disorders.

Results: Population-weighted mean prevalence rates in severe mental illness were: physical abuse 47% (range 25-72%), sexual abuse 37% (range 24-49%) and PTSD 30% (range 20-47%). Compared to men, women showed a higher prevalence of sexual abuse in schizophrenia spectrum disorder, bipolar disorder and mixed diagnosis groups labelled as having severe mental illness.

Conclusions: Prevalence rates of interpersonal trauma and trauma-related disorders were significantly higher in severe mental illness than in the general population. Emotional abuse and neglect, physical neglect, Complex PTSD and dissociative disorders have been scarcely examined in severe mental illness.

Keywords: childhood trauma; sexual abuse; physical abuse; emotional abuse; neglect, posttraumatic stress disorder; complex posttraumatic stress disorder; dissociative disorder; severe mental illness.

2.1 INTRODUCTION

Trauma exposure and posttraumatic stress disorder (PTSD) have been receiving growing attention in research over the last decades. Despite this, trauma exposure and PTSD are significantly overlooked in the treatment of patients with severe mental illness (SMI): documentation of trauma and symptoms of trauma is exceptionally low in the medical records of patients with SMI. Improved recognition is thus needed to provide adequate treatment and meaningful services for this vulnerable population [1-4].

One reason for the poor recognition of trauma in patients with SMI is the overlap which often occurs between the symptoms of trauma-related disorders and the symptoms of SMI. For instance, dissociation and psychotic symptoms can be signs of both PTSD and schizophrenia [5-7]. Another reason for poor recognition of trauma in patients with SMI is that many clinicians are hesitant to pay attention to traumatic experiences in the past because they think that this could lead to further distress and impairment. There is, however, no evidence for this conviction [1, 8].

Finally, the majority of patients with SMI entered the mental health care system a long time ago when knowledge of the role of traumatic experiences in the onset and course of these disorders was limited. Among the traumatic experiences, repeated interpersonal trauma such as emotional, physical and sexual abuse, can lead to both PTSD as well as more severe trauma-related disorders like Complex PTSD and dissociative disorders. It has further been documented that a history of interpersonal trauma exposure and the existence of trauma-related disorders negatively affects the course of SMI [2, 9, 10]. Despite this, the prevalence of interpersonal trauma exposure and trauma-related disorders in people with SMI has been scarcely investigated.

In order to gain insight into interpersonal trauma exposure and trauma-related disorders among patients with SMI, we conducted a systematic review of the relevant research literature with the following research question in mind:

> *What is the prevalence of interpersonal trauma exposure and trauma-related disorders in* patients *with severe mental illness (SMI) receiving mental health care?*

As severe mental illness and trauma-related disorders are the central concepts in this review, their definitions — which are still developing— will first be considered below.

Severe mental illness

The concept of SMI often lacks clarity and specificity. 'SMI' is the abbreviation commonly used for the following: severe mental illness, serious mental illness or severe and persistent mental illness. When Schinnar et al. (1990) [11] compared 17 definitions of SMI used in the USA between 1972 and 1987, they decided that the optimal definition was the one provided by the National Institute of Mental Health (NIMH) [12] with the following criteria: a diagnosis of non-organic psychosis or personality disorder; duration in terms of prolonged illness and long-term treatment; and disability including three of eight criteria: (a) social behaviour demanding a mental health intervention; (b) limited ability to obtain assistance; (c) impaired activities of daily living and basic needs; (d) impaired social functioning; (e) impaired performance in employment or (f) non work (homemaking); (g) vulnerability to stress; (h) disability that causes dependency [11, 12]. Kessler et al. (2003) [13] defined SMI as any 12-month DSM-IV disorder, other than a substance use disorder, with a global assessment of functioning (GAF) score < 60 [13].

In Europe, Ruggeri et al. (2000) [14] have operationalized the NIMH criteria for SMI along two dimensions: duration of treatment (≥ 2 years) and degree of dysfunction (GAF-score ≤ 50 or 70 depending on the primary diagnosis) for any mental disorder [14].

Post-traumatic stress disorder

In the DSM-IV-TR, post-traumatic stress disorder (PTSD) is classified as an anxiety disorder which follows a traumatic event and entails intense fear and/or feelings of helplessness. Symptoms are divided into three clusters: (a) intrusions in the form of re-experiencing the trauma via nightmares, obsessive thoughts and/or flashbacks; (b) avoidance of situations, people and/or objects which remind the patient of the traumatic event; and (c) increased anxiety in general, possibly with a heightened startle response and alertness [15].

Complex post-traumatic stress disorder

PTSD captures only a limited aspect of posttraumatic psychopathology, especially in victims with severe and prolonged trauma. Herman (1992) [16] has identified seven symptom clusters for these victim groups: dysregulation of (a) affect and impulses; (b) attention or consciousness; (c) self-perceptions; (d) perceptions of the perpetrator; (e) relations with others; (f) somatization; and (g) systems of meaning. This constellation of symptom clusters is referred to as Complex PTSD or disorder of extreme stress not otherwise specified (DESNOS) but classified in the DSM-IV as PTSD with associated features [15-18].

Bryant (2010) [19] has argued that emotion dysregulation is the core feature of Complex PTSD. Dysregulated affect and impulses, self-perceptions and relations with others are also highly characteristic of personality disorders, particularly borderline personality disorder (BPD) [15, 19, 20]. This makes BPD difficult to distinguish from Complex PTSD. Lewes & Grenyer (2009) [21] reviewed the ongoing controversy on the nature of the relationship between Complex PTSD and BPD concluded that these disorders often cohere, but are separate phenomena [21].

Dissociation and dissociative disorders

It has been further argued in the literature that dissociation is a core feature of Complex PTSD. Van der Hart et al. (2005) [22] have postulated that traumatization essentially involves some degree of division or dissociation of the psychobiological systems which constitute identity [22]. Dissociative identity disorder (DID) and dissociative disorder not otherwise specified (DDNOS) have indeed been found to be highly correlated with a history of severe and prolonged traumatic experiences (82%) and therefore were considered as trauma-related disorders in such cases [23-25].

Based on this overview of concepts, we used the following definitions in our review: SMI was defined as any mental disorder, other than a substance use disorder, with the following two dimensions: duration of mental illness and obvious dysfunction. PTSD, Complex PTSD, DID and DDNOS were considered as trauma related disorders. BPD was considered as a separate disorder.

2.2 METHODS

Operationalization of concepts

In this review the two dimensions of *SMI* were operationalized as (1) duration of mental illness ≥ 2 years [14] and (2) obvious dysfunction as a GAF-score ≤ 60 or a clear description of a minimum of three disabilities according to the NIMH criteria for SMI [12, 13]. *Interpersonal trauma* was defined as

involving any of the following traumatic experiences: emotional abuse (EA), emotional neglect (EN), physical abuse (PA), physical neglect (PN), and/or sexual abuse (SA) in childhood and/or adulthood. *Trauma-related disorders* were considered present when a diagnosis had been made of: PTSD, PTSD with associated features, Complex PTSD, DESNOS, DID and/or DDNOS.

Search strategy

The Medline, PsycINFO, Embase, and CINAHL databases were searched for the period between 1980 and searched from 1980 through 2010. The subject headings and keywords were as follows. For *SMI*: severe mental illness, schizophrenia/psychotic disorders, bipolar disorders, major (chronic) depression/major depressive disorders, anxiety disorders, eating disorders and personality disorders. For *interpersonal trauma exposure*: child abuse, emotional abuse; emotional neglect; physical abuse; physical neglect; sexual abuse; physical assault and sexual assault. For *trauma-related disorders*: PTSD, Complex PTSD, DESNOS and Dissociative disorders. *Prevalence* was searched using the terms: prevalence, co-morbidity and risk factors.

All of the keywords for trauma and prevalence were first combined. Then these words were combined with each mental disorder. The exact search strategy is outlined in Supplemental File 1.

Selection criteria

Inclusion criteria for peer-reviewed publications using adult study populations (≥ 18 years) were:

- SMI was labelled as such or one of the following mental disorders was mentioned: schizophrenia spectrum disorders, bipolar disorders, major depression/depressive disorders, anxiety disorders, eating disorders or personality disorders
  - classified in DSM-III, DSM-IV or DSM-IV-tr
  - *SMI* determined on basis of both dimensions:
    - duration of illness and/or treatment (≥ 2 years)
    - obvious dysfunction (GAF ≤ 60 or clear description of minimum of three impairments according the NIMH definition)

and

- report of prevalence of *interpersonal trauma exposure* with:
- specific description
  - type of abuse, reference period (childhood, adulthood, lifetime)
  - description of the diagnostic instrument used

and

- report of prevalence of *trauma-related disorders*:
  - PTSD, Complex PTSD (PTSD with associated features or DESNOS), DID and/or DDNOS
  - relevant diagnostic instruments were described

The *exclusion criteria* for our review were:

- substance use disorders as only diagnosis
- developmental disorders; delirium, dementia, amnesia or other cognitive disorders with a physical origin
- forensic and/or imprisoned populations

Selection

Figure 1 shows the selection of the publications for this review. Of the initial 6299 unique hits, 4422 publications were excluded because the title did not mention SMI and/or interpersonal trauma or trauma-related disorders, or the title mentioned the age ≤ 18. The abstracts from the remaining 1877 publications were independently reviewed by two researchers. Of these, 104 described the prevalence of interpersonal trauma exposure or trauma-related disorders in SMI and the entire publication was therefore reviewed by three researchers independently. In the end, 33 publications described the prevalence of *both* trauma exposure and trauma-related disorders in SMI and were thus selected for inclusion in the review.

Those studies in which SMI was explicitly mentioned only included the following disorders: schizophrenia (spectrum disorder), bipolar disorder, major depressive disorder and personality disorder. Anxiety disorders and eating disorders were never characterized as SMI in the selected publications and contained insufficient information about duration of illness and obvious dysfunction. For this reason, anxiety or eating disorder as the primary diagnosis were excluded from our review although the prevalence of trauma in such disorders is notable [26-29]. One study of bipolar disorders was also excluded from our review due to the exclusion of the severely ill subgroup of patients [30].

Data extraction

The following data were extracted from the 33 publications included in the review:

1. Population characteristics: gender, age, country, care setting, research type
2. Primary diagnosis for SMI
3. Diagnostic instruments used
4. Prevalence rates for interpersonal trauma: type (EA, EN, PA, PN, SA), reference period (childhood, adulthood, lifetime)
5. Prevalence rates for trauma-related disorder: description of diagnosis
6. General conclusions of study

Quality assessment

The following quality aspects of the studies included in the review were assessed:

a. Study design
b. Sampling: inclusion and exclusion criteria; (non)response
c. Use of diagnostic instruments to determine primary diagnosis (SMI)
d. Use of diagnostic and research instruments to measure trauma exposure and trauma-related disorders

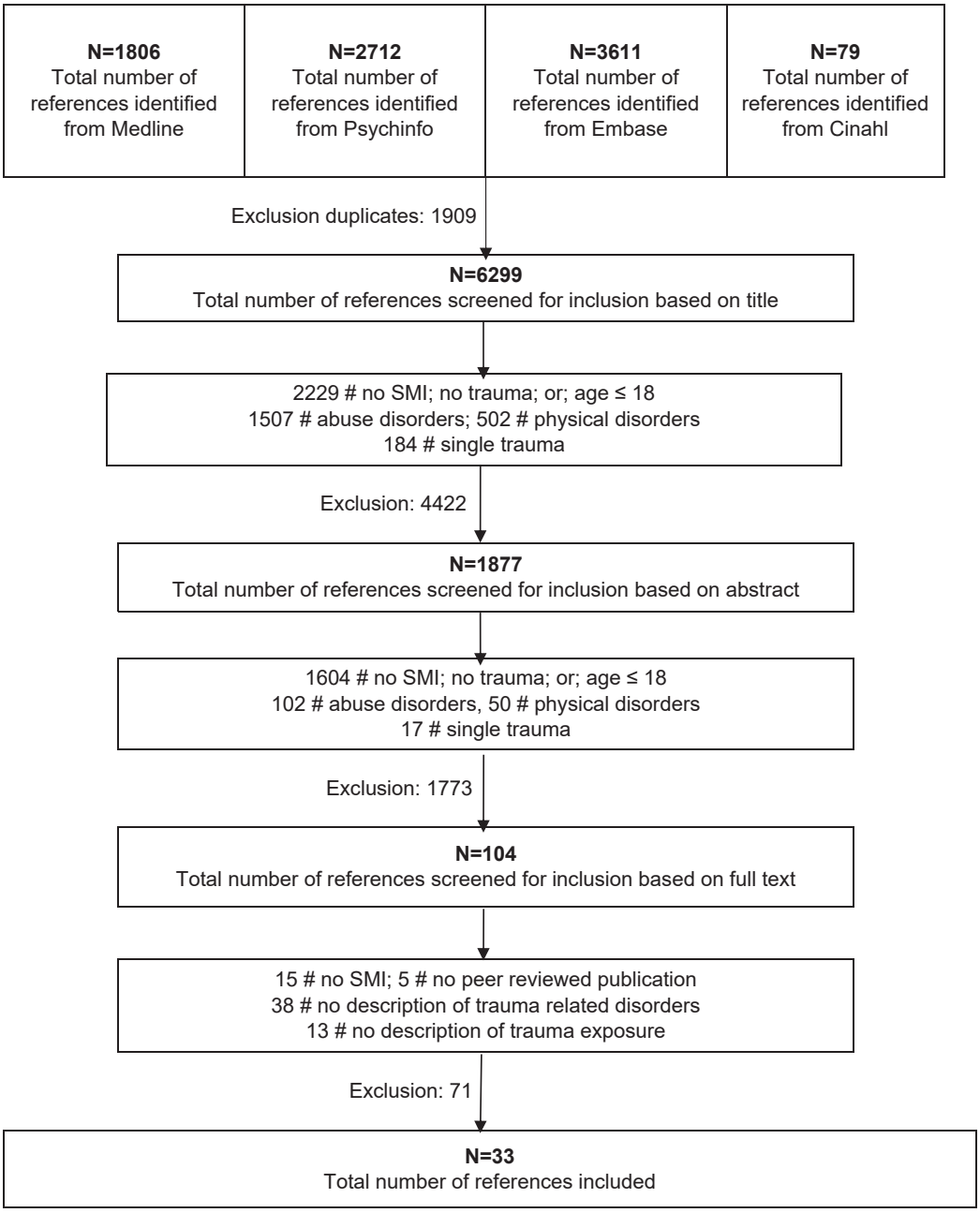

Figure 1. Selection in scheme.

2.3 ANALYSIS

Prevalence rates were determined according to diagnostic group and gender. To facilitate comparison of the prevalence rates, population-weighted means were calculated for each of the diagnostic groups. This was also done for gender when reported. A formal meta-analysis was not performed because of the wide variety of objectives and research designs in the studies, the heterogeneity of the instruments used to assess interpersonal trauma exposure and the affected stage of life e.g. childhood, adulthood or lifetime.

2.4 RESULTS

In the 33 studies included in our review, the following disorders were addressed: bipolar disorder (8), major depressive disorder (6), schizophrenia spectrum disorder (7), personality disorder (5) and mixed diagnostic groups, explicitly labeled as SMI (7). All publications described the prevalence of interpersonal trauma exposure, and all but one [31] described the prevalence of PTSD. One publication described the prevalence of Complex PTSD [32] and two reported the prevalence of DID and/or DDNOS [24, 31]. The characteristics of the studies are outlined in Table 1.

Quality of the included studies

All 33 publications fulfilled the required inclusion criteria for primary diagnosis and age. Eight publications described additional selection criteria and also mentioned training of the diagnostic interviewers (Table 1). The other publications described only additional selection criteria or the training of the interviewers but not both. The instruments used for the primary diagnosis in the 33 studies are reported in Table 1 and described further in Supplemental File 2. The diagnostic instruments used to assess trauma exposure and trauma-related disorders are similarly reported in Table 1 and described further in Supplemental File 3.

Prevalence of physical abuse (PA), sexual abuse (SA) and PTSD according to diagnostic group and reference period

Prevalence rates of PA and SA were examined in all 33 studies according to reference period (i.e., childhood only, adulthood only, both childhood and adulthood, or lifetime) (Figure 2). Two studies considered PA and SA together and could not be shown in the figures. These combined lifetime prevalence rates were 40% and 53%, respectively [33, 34].

In those studies reporting on both the adult and childhood prevalence of PA, adult PA tended to be higher than childhood PA for schizophrenia spectrum disorders, personality disorders and SMI (mixed diagnoses group). Similarly, the adult prevalence of SA tended to be higher than the childhood prevalence for SMI and personality disorders (Figure 2).

Table 1. Study design, population characteristics, and instruments used in the 33 studies of this review.

											Instruments for assessing		
	Author	Study design	Country	N	SC	Response	Mean age / SD or range	Setting	Diagnosis / disorder	TI	Diagnostis	Trauma exposure	PTSD
Bipolar disorder													
1	Assion et al., 2009	Prevalence study	Germany	N= 74 (f=44)	Y		48.3 (13)	In- and outpatient	Bipolar-I: euthymic/ mild/ moderate depressed	Y	MINI/ HAM-D/ YMRS	PDS	PDS / CAPS
2	Goldberg et al., 2005	Prevalence study	USA	N=100 (f=49)	N		42.6 (13.2) 36.6 (9.7) (T)	Inpatient	Bipolar-I (73) Bipolar-II (27)	N	SCID-I/ HAM-D/ YRMS	CTQ/ TSS	SCID-I
3	Kauer et al., 2007	Correlation study	Brazil	N= 163 (f=117)	N		42.5 (SD 11.6)	Outpatient	Bipolar-I Bipolar-II	N	Chart DSM-IV/ HDRS/ YMRS	SCID-I (critera A1 and A2)	SCID-I-PTSD module
4	Leverich et al., 2002	Correlation study	USA	N=651 (f=274)	N		41 (12)	Outpatient	Bipolar –I (475) Bipolar-II (137) Bipolar NOS (12)	N	SCID-P/ IDS/ YMRS	Patient Quest. with items: EA, PA, SA	SC-I
5	Maguire et al., 2008	Prevalence study	Northern Ireland UK	N=60 (f=34)	Y	non-resp 24 drop-out 15	49 (25-70)	Outpatient	Bipolar-I Bipolar II	Y	Chart DSM-IV/ BDI	CHQ/ THQ	PDS
6	Meade et al., 2009	Treatment study	USA	N=90 (f=41)	Y	non-resp 57 drop-out 42	40.6 (± 11.7)	In- and outpatient	Bipolar-I with SUD	Y	SCID-I/ HAM-D/ YRMS	ASI: 2 items	SCID-I
7	Neria et al., 2005	Correlation study	USA	N=109 (f=58)	N	response 88,7%	m=23 (15-54) f=29 (16-57)	Inpatient	Bipolar with psychotic features	N	SCID-I-DSM-III and IV	CIDI-PTSD/ SCID-PTSD	CIDI-PTSD/ SCID-PTSD
8	Neria et al., 2008	Prevalence study	USA	N=96 (f=64)	y		50 (18-70)	Outpatient	Bipolar spectrum	N	MDQ/ PDQ	LES	PCL-C
Major depressive disorder													
9	Bernet et al., 1999	Correlation study	USA	N=47 (f=24)	Y		39.0	Outpatient	Major Depressive Disorder	Y	SCID-I/ HRSD	CTQ	SCID-I
10	Carlier et al., 2000	Prevalence study	The Nether-lands	N=69 (f=45)	Y		45.4 (12.9)	Outpatient	Major Depressive Episode	N	SCID-DSM-III-R	LTE	SI-PTSD
11	Gaudiano et al., 2009	Correlation study	USA	N=623 (f=397)	N		38.5 (12)	Outpatient	Major Depressive Disorder (psychotic n=32)	Y	SCID-I/ SIDP-IV/ CGI	CTQ	SCID-I
12	Oquendo et al,. 2005	Correlation study	USA	N=230 (f=180)	N		41.7 (0.6)	In (113) outpatient (117)	Major Depressive Episode	Y	SCID-I/ SCID-II/ HMDRS/ BDI	SCID-I	SCID-I
13	Zimmerman et al., 1999	Correlation study	USA	N=235 (f=152)	N		40.6 (14.03)	Outpatient	Major Depression (psychotic n=19)	Y	SCID-I.	SCID-PTSD	SCID-PTSD
14	Zlotnick et al., 2001	Correlation study	USA	N=235 (f=152)	N		40.6 (14.0)	Outpatient	Major Depression	Y	SCID-I/ SIDP/ SADS	SCID-PTSD	SCID-PTSD

Table 1 (continued)

	Author	Study design	Country	N	SC	Response	Mean age / SD or range	Setting	Diagnosis / disorder	TI	Instruments for assessing: Diagnosis	Trauma exposure	PTSD
Schizophrenia spectrum disorder													
15	Beattie et al., 2009	Correlation study	Northern Ireland (UK)	N=47 (f=22)	N		37.5 (11.5)	Outpatient <12 mnths	Schizophrenia (25) Schizoaffective (7) Other psychosis(10)	N	KGV:pos./ neg./ affect symptoms	CTQ/ THQ	IES-R
16	Calhoun et al., 2007	Prevalence study	USA	N=165 (f=0)	N		48 (7.8)	Inpatient (veterans)	Schizophrenia Schizoaffective	Y	SCID-I	SAEQ/ CTS-R/ CES	PCL
17	Kilcommons et al., 2005	Prevalence study	UK	N=32 (f=7)	N	non-resp 3%	34.5 (10.0)	Outpatient	Schizophrenia spectrum	N	Chart DSM-IV/ PANSS	THQ	PSS-R
18	Lommen et al., 2009	Prevalence study	The Nether-lands	N=33 (f=10)	Y	non-resp 40 drop-out 2	42.3 (10.6)	Outpatient	Schizophrenia (23) / Schizoaffective (10)	N		THQ-R	PSS-SR / PCTI
19	Resnick et al., 2003	Correlation study	USA	N=47 (f=30)	N		44.1 (9.7)	Outpatient	Schizophrenia (39) Schizoaffective (8)	Y	SCID-I/ PANSS	THQ-R	CAPS
20	Rosenberg et al., 2007	Correlation study	USA	N=569 (f=183)	N		42 (9.0)	Outpatient	Schizophrenia (288) Schizoaffective (98)	N	Chart DSM-IV (81%)/ SCID (19%)	SAEQ/ CTS	PCL
21	Ross et al., 2004	Prevalence study	USA	N=60 (f=23)	N	non-resp 3	40.1 (13.4)	In- and outpatient	Schizophrenia	N	Chart DSM III-R/ SAPS/ SANS		DDIS / DES-T
Personality disorder													
22	Barnow et al., 2005	Prevalence study	Germany	N=51 (f=44)	Y		26.5 (±7.6)	Inpatient	Borderline Personality	Y	SCID-II/ BPI/ DIA-X (CIDI)	SCID-I-PTSD	SCID-I-PTSD / SIDES
23	Bosch vd et al., 2003	Correlation study	The Nether-lands	N=63 (f=63, addicted)	Y		34.9 (7.7).	Inpatient	Borderline Personality (addicted 34)	Y	SCID-II/ PDQ4+	STI	SCID-I-PTSD
24	Sar et al., 2003	Prevalence study	Turkey	N=25 (f=20)	Y	respons 79,5%	30.0	Outpatient	Borderline Personality	Y	SCID-II (DSM-III-R)	History Form for Childhood Abuse and Neglect	SCID-PTSD/ DES/ DDIS/ SCID-D
25	Zlotnick et al., 2003	Correlation study	USA	N= 266 (f=186)	y		31.5 (7.5)	In- and outpatient	Borderline Personality	N	DIPD-IV/ SCID-I/ SNAP	CEQ	SCID-I / DIPD-IV
26	Yen et al., 2002	Correlation study	USA	N=653 (f=324)	y	dropout 15	32.8 (8.0)	In- and outpatient	Borderline(176,f=123), Schizotypal (86, f=39), Avoidant (153, f=100), Obs. Compulsive (153, f=62)	N	DIPV-IV/ SCID-I	SCID-I trauma module	SCID-I trauma module

Table 1 (continued)

	Author	Study design	Country	N	SC	Response	Mean age / SD or range	Setting	Diagnosis / disorder	TI	Instruments for assessing: Diagnosis	Trauma exposure	PTSD
Severe mental illness													
27	Cusack et al., 2006	Prevalence study	USA	N=142 (f= 63)	Y		46.2 (11.6)	Outpatient	Schizophrenia, Bipolar Major depression	N	Chart Review Instrument	TAA	PCL
28	Davies-Netzley et al., 1996	Correlation study	USA	N=120 (f=120)	Y		37.0 (18-63)	Outpatient	Schizophrenia (57) Bipolar (26) Major Depression (37)	Y	DIS (DSM-III-R)/ CES-D	Specified questions about child abuse	PTSD section of DIS
29	Ford et al., 2007	Prevalence study	USA	N=35 (f=35)	N		41.0 (29-68)	Outpatient	Schizophrenia, Bipolar, Major depression	Y	SCID-I	TESI	CAPS / SIDES
30	Goodman et al., 1999	Reliability study	USA	N=50 (f=29)	Y	resp 80% drop-out 3	m=37.6 (7.3) f=42.1 (7.6)	Outpatient	Schizophrenia (32) Bipolar (16) Psychotic (2)	N	SCID-I	SAEQ/ CTS-2 (PA/SA/injury)	PCL-S
31	Lu et al., 2008	Correlation study	USA	N=254 (f=112)	N	non-resp 20	42.9 (11.0)	In- (109) outpatient (145)	Major Depression 100) Bipolar (154)	N	Chart (81.0%) SCID-I (19.0%)	SAEQ/ CTS-R	PCL
32	Mueser et al., 1998	Prevalence study	USA	N=275 (f=153)	N	non-resp 10%	40.0(11.6)	In- (92) outpatient (183)	Schizophrenia (64), Schizo-affective (30), Bipolar (50), Depression (65), Borderline (22), Other Personality (10) Other diagnosis (34)	Y	Chart (81.0%) SCID-I (19.0%)	THQ (child-hood and adulthood separated asked)/ CVS	SCID / PCL-S
33	Mueser et al., 2004	Prevalence and correlation study	USA	N=782 (f=321)	N	response 87%	age≥18	Outpatient	Schizophrenia (363), Schizo-affective (163), Bipolar (141), Major depression (78), Other diagnosis (26)	N	Chart (81.0%) SCID-I (19.0%)	SAEQ/ CTS (child)/ CTS-2 (adult)	PCL

SC: Selection criteria other than inclusion criteria, TI: Trained interviewers

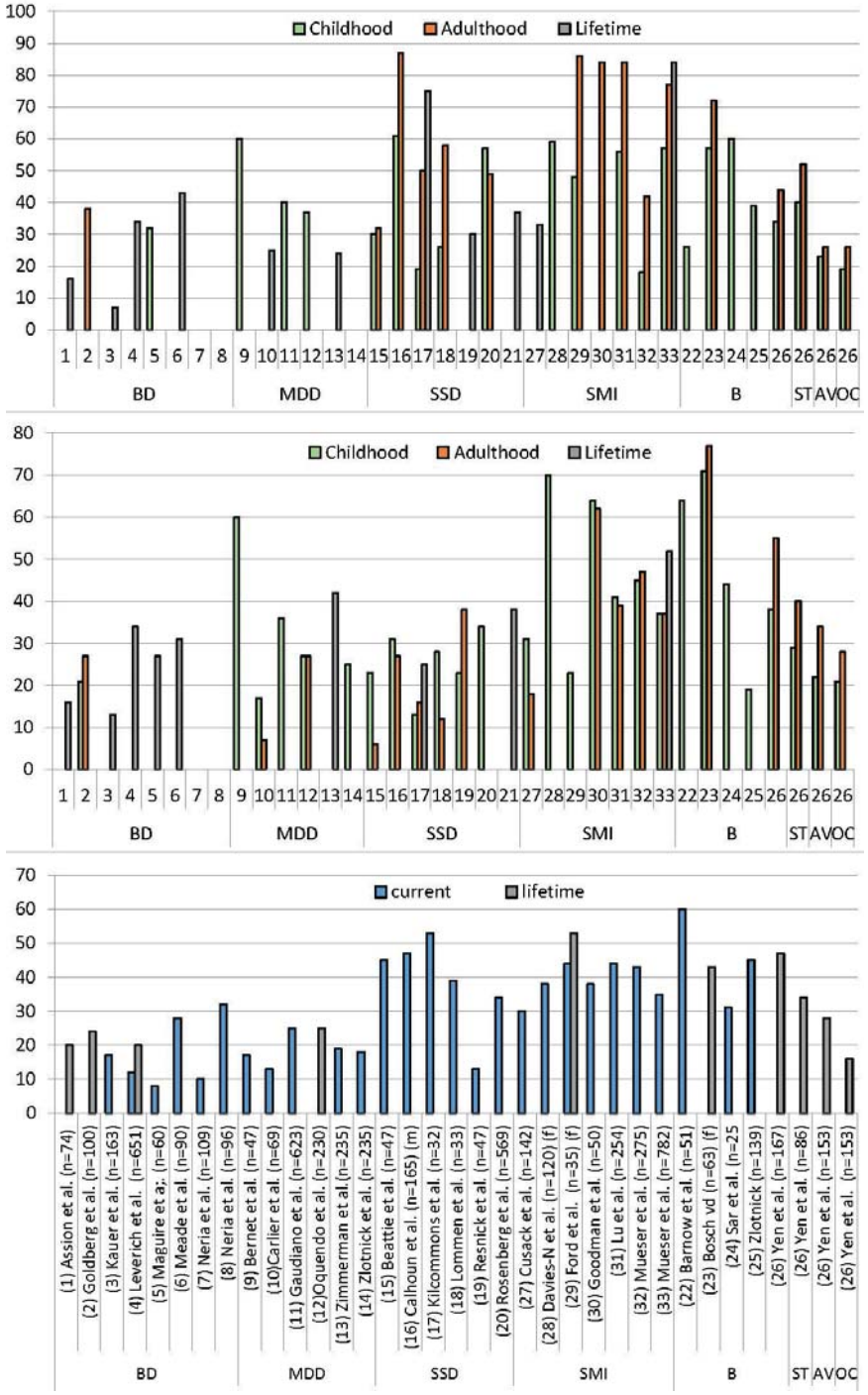

Figure 2. Prevalence rates for physical abuse, sexual abuse, and PTSD by disorder and reference period. BD, bipolar disorder; MDD, major depressive disorder; SSD, schizophrenia spectrum disorder; SMI, severe mental illness; B, borderline; ST, schizotypal; AV, avoidant; OC, obsessive compulsive disorder.

Prevalence of PA, SA and PTSD across diagnostic groups

Figure 3 shows the mean prevalence rates for PA, SA and PTSD weighted according to population size. When more than one rate was given for a particular type of trauma exposure (e.g., both childhood and adulthood), the highest prevalence rate was adopted. Prevalence rates for PA and PTSD were relatively low in bipolar and major depressive disorder. The mean prevalence of PA was most high in schizophrenia and SMI while the mean prevalence of SA and PTSD was most high in BPD and SMI.

Prevalence of PA, SA and PTSD according to diagnostic group and gender

The prevalence of PA and SA according to gender was examined in 11 studies and involved the following diagnostic groups: bipolar disorder, schizophrenia spectrum disorder and SMI. Three of these studies also described prevalence according to gender for PTSD (Figure 4). Prevalence rates for SA were significant higher for women than for men, but less so for PA.

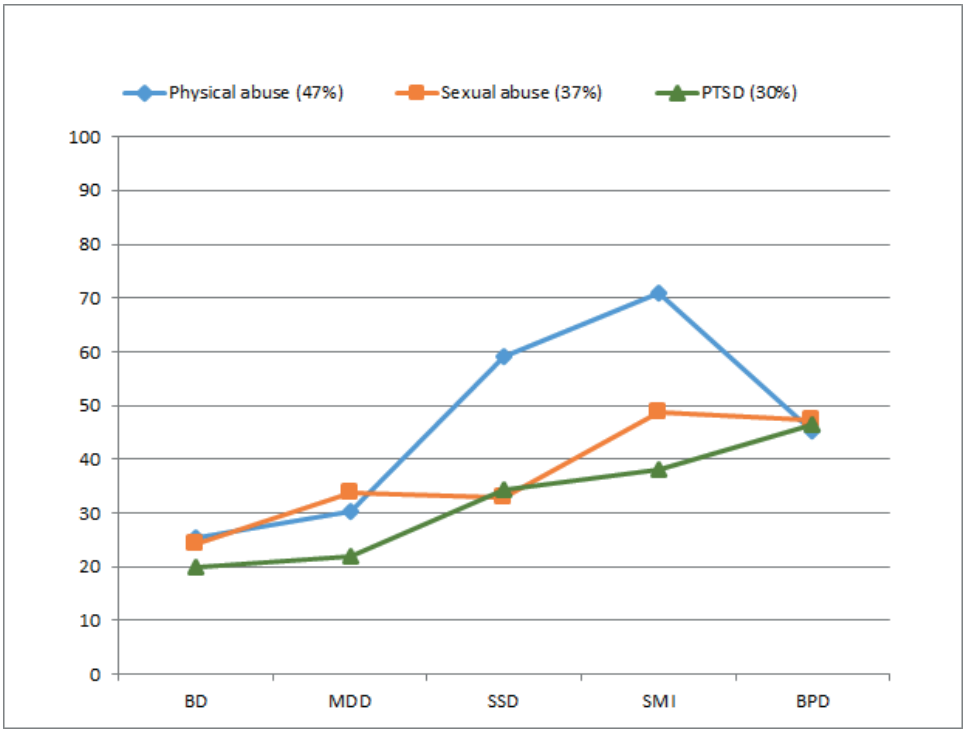

Figure 3. Overview of mean prevalence of physical abuse, sexual abuse, and PTSD by diagnostic group (BD Bipolar disorder, MDD Major Depressive disorder, SSD Schizophrenia Spectrum disorder, SMI Severe Mental Illness, BPD Borderline Personality disorder).

Prevalence of EA, EN and PN according to diagnostic group and reference period

Estimates of the prevalence of emotional abuse (EA) in bipolar disorder were provided in only two studies: 43% for childhood [35] and 6% for lifetime [36]. This large difference could reflect differences in the diagnostic instruments used in the these studies (see Table 1). The childhood prevalence of EA in major depressive disorder was reported to be 39% by [37] and 49% by [38].

The prevalence of childhood EA was highest in the psychotic subgroup of major depression with 53% [37]. In a single study of schizophrenia, the childhood prevalence of EA, emotional neglect (EN) and physical neglect (PN) were found to be 13%, 13% and 6%, respectively [39]. In BPD the prevalence of childhood EA was 60-63% [24, 40]. The prevalence of total neglect in BPD was 60-88% [40-42].

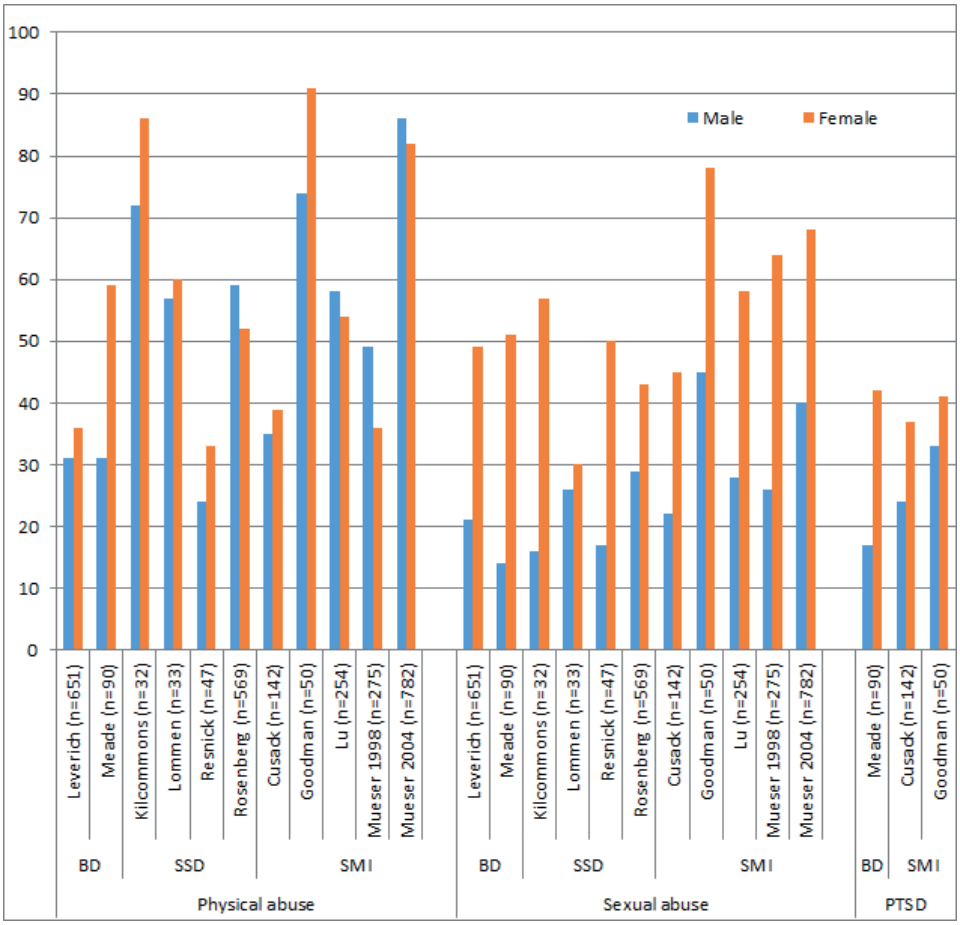

Figure 4. Prevalence rates for physical abuse, sexual abuse, and PTSD by disorder and gender. BD, bipolar disorder; SSD, schizophrenia spectrum disorder; SMI, severe mental illness.

Complex PTSD and dissociative disorders

Complex PTSD in schizophrenia was investigated and present in one study, but the prevalence rate was not reported [43]. The current prevalence of Complex PTSD in BPD was 31% [32]. The prevalence of DID in schizophrenia has been reported to be 16% [31]. And the current prevalence of DID in BPD has been reported to be 24% and that of DDNOS in BPD to be 36% [42]. In this study DID only appeared in patients with both BPD and a history of trauma exposure and it also correlated with the highest prevalence of childhood trauma.

Notable clinical findings

Co-morbidity

Information on co-morbid conditions was reported in 20 publications. Of these, 13 compared co-morbidity for traumatized versus not traumatized subgroups and found a higher degree of co-morbidity for Axis I and/or Axis II disorders for all of the traumatized subgroups. The prevalence of co-morbid substance use disorders was also significantly higher for the traumatized subgroups and negatively influenced the course of mental illness [31, 32, 38, 43-52].

Influence of interpersonal trauma exposure and trauma-related disorders on the course of mental illness and severity of symptoms

Childhood sexual abuse (SA) and childhood emotional abuse (EA) were associated with an 8-9 year earlier onset of illness in major depressive disorder [38]. Childhood physical abuse (PA) and childhood SA were strongly associated with PTSD in psychotic subtypes of major depressive disorder [53]. Childhood trauma exposure had a negative effect on the course of illness in schizophrenia spectrum disorder [50]. Severity of trauma exposure was associated with positive symptoms in schizophrenia [5, 31, 54]. SMI patients with a history of both PA and SA attempted suicide five times more frequently [43]. The number of types of trauma exposure also predicted PTSD in SMI [55].

Co-morbid lifetime PTSD predicted a worse clinical outcome for bipolar disorder: a six-year earlier start of the symptoms, more severe symptoms, more suicide attempts and ultra rapid cycling of mood swings [36, 46, 52]. PTSD was associated with more severe symptoms and more suicide attempts for major depressive disorder; it was also four times more present for the psychotic subtypes of major depressive disorder [56] than for the non-psychotic subtypes [53, 57] PTSD related significantly to Axis-I co-morbidity and severe emotion dysregulation in BPD [40]. Complex PTSD, DID and DDNOS related significantly to a chronic course of illness, severe clinical conditions, more self-destructive behaviour and suicide attempts in BPD [32, 42].

2.5 DISCUSSION

Main findings

The mean prevalence rates in SMI ranged according to the diagnostic group and were: PA 47% (range 25-72%), SA 37% (range 24-49%) and PTSD 30% (range 20-47%). Compared to men, women showed a higher prevalence of SA in schizophrenia spectrum disorder, bipolar disorder and mixed diagnosis groups labelled as having severe mental illness.

The prevalence rates in SMI were significantly higher than those in the general population. More specifically, the prevalence in SMI as compared to the general population was 47% versus 21% for PA

and 37% versus 23% for SA. Gender differences in the prevalence of SA in SMI (20-34% for men, 44-64% for women) were roughly comparable to that in the general population (14% for men, 32% for women) [27]. The PTSD prevalence of 30% in SMI was also significantly higher than the PTSD prevalence of 7% among a general population of adult Americans [58, 59].
A 35% prevalence of Complex PTSD in BPD was reported in one study and distinguished from a 61% prevalence of PTSD [32]. The prevalence of Complex PTSD (DESNOS) in the general population has been scarcely examined, so further comparison was not possible. One study nevertheless reported a prevalence of 1.0 % [60]. The prevalence of dissociative identity disorder (DID) was reported to be 16% in schizophrenia [31] and 24% in BPD; for DDNOS, this rate was reported to be 36% in BPD [42]. The prevalence of DID in the general population has been found to vary from 0.4% to 3.1%, depending on the assessment instrument used [9, 24].

Validity

Our literature search covered a period of 30 years and was conducted independently on four databases. The publications included in the review were selected by three independent reviewers. The primary diagnoses for the patients in the studies we reviewed were usually confirmed via structured interviews like the SCID-I, SCID-II or MINI (see supplemental file 2). In three of the 33 studies, only 19% of the chart diagnoses were confirmed using the SCID-I; in six of the studies, only the chart diagnosis were used. The severity of symptoms was screened for in twelve of the studies — mostly for bipolar disorder (HAM-D, YMRS), major depressive disorder (HAM-D, BDI) and sometimes schizophrenia spectrum disorder (PANSS) (see Table 1).
Trauma history was assessed in the 33 studies we reviewed using 19 different instruments. Sufficient information was generally provided by the different instruments although they differed with regard to the questions used to assess life stage and type of interpersonal trauma. As a result, the prevalence rates were difficult to compare across studies and the population-weighted prevalence rates should be interpreted with caution.
The quality of the information provided about sampling and severity of illness differed across the studies. In the mixed diagnoses groups characterized as SMI schizophrenia spectrum disorders and/or other psychotic disorders were highly represented (about 60%). These mixed diagnoses groups consisted probably of the most impaired patients showing high co-morbidity, a worse course of illness and the highest prevalence of trauma exposure and PTSD.

Possible limitations

The aim of our literature search could not easily be related to a limited set of search terms. The search strategy we used was exhaustive but may nevertheless not have captured all relevant studies. Nearly all studies were carried out in the USA or Western Europe, moreover, with the exception of one in Brazil [36]. Inclusion of only Dutch, English, French and German language publications may have led to a loss of information.
The aim of our review was to identify the prevalence of interpersonal trauma exposure and trauma-related disorders in SMI. Exclusion of publications which attended to *only* interpersonal trauma exposure or *only* trauma-related disorders may also thus have led to a loss of relevant information. Some publications only reported regression coefficients but not the original prevalence rates and could not be included.

Trauma, psychosis and dissociation

PA and SA in childhood and adulthood were markedly high in psychotic disorders (PA 59%, range 32-87%; SA 33%, range 23-38%). In the SMI group, PA was 71% (range 33-86%) and SA was 49% (range 23-70%). In the psychotic subgroups of major depressive disorder, childhood PA was high (53-60%) and childhood SA was even higher (59-60%) [37, 53]. Janssen et al. (2004) [61] also found that early childhood trauma such as physical and sexual abuse increased the risk of developing positive psychotic symptoms in adulthood in a dose–response manner [61]. The prevalence of PTSD was 34-48% in psychotic disorders and 58-65% in psychotic subgroups of major depressive disorder.

The relationship between trauma and psychosis is nevertheless not straightforward. Trauma can certainly cause psychosis but psychosis can conversely cause PTSD and both psychosis and PTSD can be part of a spectrum of responses to a traumatic event [62, 63].

Two of the 33 studies included in our review attended to psychosis as an internal threat and causal factor in the occurrence of PTSD. "Internal threat" is not considered an A1-criterion for PTSD in the DSM-IV, but Lommen et al. (2009) [64] have reported a prevalence rate of 39% including internal threat and 18% excluding internal threat for PTSD [64]. Resnick et al. (2003) [54] have similarly reported a prevalence rate of only 13% excluding internal threat [54]. The remaining four studies attending to psychosis and schizophrenia did not report on the A1-criterion for PTSD and the extent to which internal threat related to PTSD in these studies was therefore unclear.

Psychosis and dissociation are hard to distinguish in clinical practice [5-7]. When Ross and Keyes (2004) [31] examined dissociation in schizophrenia, those patients showing dissociation were found to have more severe trauma histories, more co-morbidity and higher scores for both positive and negative symptoms of schizophrenia when compared to patients without dissociation [31]. Read et al. (2005) [65] have further stated in their review of childhood trauma, psychosis and schizophrenia that hallucinations are strongly related to abuse in childhood and more or less memories of the traumatic events. Conceptualization of hallucinations as dissociative memories of traumatic events may thus be valuable for understanding the relations between trauma, psychosis and dissociation [65]. And viewed from this perspective, 'Schneiderian and other positive psychotic symptoms follow logically from the existence of a structurally dissociated psyche'. McCarthy-Jones & Davidson (2012) [66] have also recently described the lack of love experienced by abused people. Traumatic events may lead to auditory hallucinations with critical voices related to frightening experiences and supportive voices related to lack of love and support [66].

Psychotic symptoms may thus cohere or fall in with dissociative symptoms and possibly be the result of the same underlying mechanism. Within this context, however, Moskowitz (2011) [67] points to conflicting paradigms: the trauma-dissociation paradigm which is focussed on life events versus the neo-Kraepelinian paradigm which is genetically and biologically based. He suggests that the integration of the paradigms into a broader bio-psycho-social paradigm could be more useful for both future research and treatment [67].

Implications of our findings

In clinical practice, assessing interpersonal trauma exposure and trauma-related disorders in SMI can reduce current underreporting and lack of treatment. Trauma history can be assessed without further impairment of the patient ([1, 8, 68]. Patient reports of trauma have been shown to be reliable [2, 69]. PTSD in SMI can be treated effectively using cognitive behavioural therapy: cognitive restructuring [51, 70, 71] EMDR [3] prolonged exposure [72]. For the treatment of Complex PTSD starting with stabilizing

interventions prior to EMDR or prolonged exposure has been shown to improve the overall treatment effect [73-75]. Assessment and treatment of dissociative disorders in traumatized groups is called for in light of the severe clinical condition of such patients and their low treatment success when dissociative disorders are not recognized [9, 22, 31, 42, 65, 67, 76].
In future research, greater attention should be paid to physical neglect, emotional neglect and emotional abuse because these factors have been found to increase the risk of developing PTSD [37-39, 42, 77]. Complex PTSD and DID should be given greater attention in light of their negative influence on the course of a patient's mental illness and quality of life [32, 42, 65].

2.6 CONCLUSION

The prevalence of interpersonal trauma exposure and PTSD in severely mentally ill patients is significantly higher than in the general population. For physical abuse, sexual abuse and PTSD the prevalence rates differ depending on the type of mental disorder: lower rates of trauma are found for bipolar and major depressive disorder but higher rates are found for schizophrenia, borderline personality disorder and groups labelled as severely mentally ill. Emotional abuse, emotional neglect, physical neglect, Complex PTSD and dissociative disorders have been scarcely examined in SMI. Traumatized patients with SMI show more severe symptoms and a worse course of illness than non-traumatized patients with SMI.

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Supplemental material

Supplemental file 1: Search History. Online available

Supplemental file 2: Measuring instruments/assessments: DSM-III and DSM-IV diagnoses with symptom scales.

Supplemental file 3: Measuring instruments/assessments: Trauma exposure, PTSD, Complex PTSD and dissociative disorders.

These files are available online: https://www.tandfonline.com/doi/full/10.3402/ejpt.v4i0.19985

“That a violent event could do this to someone’s internal spirit as well as their bodies, I believe, is hard to accept because how vulnerable we are deep inside, to the many forms of violence that surround us and that we ourselves enact”

Serene Jones, Trauma and Grace. Theology in an ruptured world

Chapter 3

Phase-based treatment of a complex severe mentally ill (SMI) case involving Complex Posttraumatic Stress Disorder and psychosis related to Dandy Walker Syndrome

Maria Mauritz

Roland van de Sande

Peter Goossens

Theo van Achterberg

Nel Draijer

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ABSTRACT

Background: In patients with co-morbid Complex Posttraumatic Stress Disorder (Complex PTSD) and psychotic disorder, trauma focused therapy may be difficult to endure. Phase-based treatment including (1) stabilization, (2) trauma focused therapy, and (3) integration of personality with recovery of connection, appears to be the treatment of choice.

Objective: To describe and evaluate the therapeutic process of a single case from a holistic perspective.

Methods: Case Report. A 47-year-old woman was treated for severe Complex PTSD resulting from repeated sexual and physical abuse in early childhood and moderate psychotic symptoms stemming from Dandy Walker Syndrome with hydrocephalus.

Results: The patient was treated with quetiapine (600-1200 mg) and citalopram (40 mg). Stabilization consisted of intensive psychiatric nursing care in the home and stabilizing group treatment for Complex PTSD. After stabilization, the following symptom domains showed improvement: self-regulation, self-esteem, assertiveness, avoidance of social activities, and negative cognitions. However intrusions and arousal persisted and were therefore subsequently treated with prolonged imaginary exposure which also included narrative writing assignments and a final closing ritual. This intensive multidisciplinary, phase-based approach proved effective: all symptoms of the Complex PTSD were in full remission. Social integration and recovery were promoted with the reduction of polypharmacy and the provision of social skills training and lifestyle training.

Conclusion: The present case shows a phase-based treatment approach with multidisciplinary collaborative care to be effective for the treatment of a case of Complex PTSD with co-morbid psychotic disorder stemming from severe neurological impairment. Replication of this promising approach is therefore called for.

3.1 INTRODUCTION

There is evidence in the literature that PTSD in patients with psychotic symptoms can be treated effectively using eye movement desensitization and reprocessing (EMDR) [1] or prolonged exposure [2, 3]. For the treatment of Complex PTSD, which is described in the DSM-IV as PTSD with associated features such as dysregulation of affect and behaviour and dissociative symptoms [4, 5] a phase-based treatment is considered to be more effective [6]. The phase-based treatment should include: (1) stabilization, (2) trauma focused therapy, and (3) integration of personality with recovery of connection. Stabilizing interventions have been shown to be effective [7, 8] and improved the overall treatment effect when they precede exposure [9, 10].
When Cloitre et al. (2011) [11] conducted a survey among expert clinicians about best practices for the treatment modalities to address Complex PTSD; several of the experts endorsed a phase-based therapy as the most appropriate approach [11]. The primary interventions involved in such an approach are the training of emotion regulation strategies; anxiety and stress management; cognitive restructuring; interpersonal skills; and the narrate on of trauma memories prior to the provision of trauma focused therapy. However there was no consensus on the expected prognosis of clinical improvement or the duration of the entire treatment. Further research including sustained symptom monitoring during the treatment process and follow-up was strongly advised.

3.2 OBJECTIVE

The use of the phase-based treatment model for Complex PTSD seems promising for clinical practice. The aim of the current study was to examine this model at a single case level by evaluating the treatment process of a patient suffering from severe psychiatric and somatic issues, dominated by Complex PTSD symptoms and psychotic symptoms. The psychotic symptoms were related to Dandy Walker Syndrome with accompanying neurological symptoms due to hydrocephalus and consisting of chronic headache, irritability and concentration problems.
The treatment was performed by a Function Assertive Community Treatment (FACT) team. FACT is a Dutch variant of Assertive Community Treatment (ACT) which provides coordinated multidisciplinary treatment and case management for SMI patients in a stable phase. Patients in an unstable phase of illness have intensive, tailor made, outreach care available to them. FACT teams foster shared caseloads [12].

Dandy Walker Syndrome and psychosis
Dandy Walker Syndrome (DWS) is a congenital malformation of the brain associated with the emergence of several neurological symptoms and cognitive impairments in early childhood. The syndrome often includes the development of cysts in the third or fourth ventricle with hydrocephalus and changes in the cerebellum resulting from these. In 10 to 20% of the patients, alarming signs and symptoms do not appear until late childhood or early adulthood. These patients often have normal psychomotor and intellectual development during childhood and some of these same patients never develop any psychopathological signs [13-15].
Patients with a late onset of the symptoms of DWS can develop neuropsychiatric symptoms such as hallucinations and delusions or severe mood impairments during the late adolescence phase or early adulthood [16, 17]. Gan et al. (2012) [18] assume a relationship with functional and structural

abnormalities of the brain and describe the overlap between psychiatric co-morbid diseases in DWS and schizophrenia or bipolar disorder [18]. Ryan, Grenier, Castro & Nemeroff (2012) [19] argue that abnormalities of the cerebellum also have been linked with the pathophysiology of schizophrenia and bipolar disorder [19]. Similarities with these disorders include the following symptoms: delusions, hallucinations and cognitive deficits. Differences are specific neurological symptoms such as severe headaches and convulsions.

3.3 CASE REPORT

Mrs. Antonia Green, a 47-year old woman with DWS, was referred to our community mental health team (FACT-team) by her psychiatrist for long-term treatment after initial treatment with pharmacotherapy for psychotic and depressive symptoms in the past.

Brief treatment history

Pharmacotherapy with quetiapine 600 mg was prescribed by the referring psychiatrist and proved to be clinically effective. Initial assessments showed both the psychotic and depressive symptoms to be in remission. The neurological symptoms of irritability and headache declined and a previous psychotic episode, which included grandiosity, did not reoccur. The depressive symptoms accompanied by suicidal ideation also disappeared. Medication was thus maintained for prophylactic reasons and, given the stability of the patient, a recovery program was initiated.

The recovery process was impeded when Mrs. Green's partner suddenly broke off their relationship. Mrs. Green had not anticipated this and was not able to cope with the loss, which severely affected her mental state and led to both symptoms of anxiety and depression. The symptoms of anxiety cumulated to psychosis with visual hallucinations pertaining to traumatic memories (i.e. seeing her abusing parents present in the bedroom).

Next, she was voluntary admitted to an acute psychiatric ward. During her stay, Mrs. Green suffered nightmares about being the victim of repeated, simultaneous, sexual abuse by three relatives around the age of three. These nightmares with traumatic memories were new to her and very frightening because she was only aware of sexual abuse around the age of thirteen. The admission seemed to have a negative impact and in consultation with the referring psychiatrist discharge was planned within one week. After discharge from the acute psychiatric ward, Mrs. Green received further intensive psychiatric care provided by the FACT-team. Mrs. Green's psychiatrist then diagnosed a Complex PTSD on the basis of the following cluster of symptoms: physical flashbacks about sexual abuse, nightmares about and re-experiencing the traumatic events, avoidance of specific triggers, low self-esteem and mistrust of others.

Biography

Mrs. Green was the youngest of five children in a farmer's family. Her family lived in a rural area and was socially very isolated. The children were not allowed to bring school friends home with them. Mrs. Green remembers her parents arguing a lot, and both being emotionally and physically abusive to the children. She reported, for example, that when she was five years old, she was forced to help her father whip her older sister with a rope. For a period of three years starting at the age of 13, Mrs. Green was sexually abused by a relative.

Mrs. Green completed her primary and secondary education without serious learning problems, but she was often bullied by her peers. She entered a vocational education program at the age of fifteen; was accepted by her peers during the program; and developed some friendships at the time. She became a certificated plumber and attained employment, but was later declared unfit for the job due to knee problems at the age of 26 (i.e. on medical grounds). She found it difficult to deal with the loss of her job. She was living with her parents at the time but wanted to live on her own. Her parents were reluctant to let her go, but she eventually moved out on her own.

The first psychiatric symptoms occurred at the age of 28 and consisted of panic attacks during the night and depressive symptoms accompanied by low self-esteem and suicidal ideation. The symptoms were related to recovered memories of her sexual abuse at the age of 13.

The traumatic events recalled by Mrs. Green were disclosed to her family members, who responded in a hostile manner and subsequently excluded her from the family. Shortly after this sequence of events, Mrs. Green's symptoms became so severe that inpatient psychiatric treatment was required. She made friends with her fellow patients.

After discharge from the psychiatric hospital, Mrs. Green got herself a dog. This greatly facilitated her to assimilation into the neighborhood. She started caring for other people's dogs thereafter and even became a professional dog breeder.

At the age of 37, there was the onset of headaches and convulsions. Hydrocephalus as a result of Dandy Walker Syndrome with one cyst was diagnosed. Three surgical interventions then followed: (1) partial resection of the cyst; (2) placement of a catheter to allow drainage; and (3) the removal of the catheter after the development of peritonitis with no surgical options left. Mrs. Green's symptoms diminished very little. Severe headaches continued despite two different rehabilitation trajectories after surgery. In this period, she suffered from a brief psychotic episode involving grandiosity about directing traffic, which she then actually tried to do one night. Eventually she became severely depressed, in part because she experienced the headaches as unbearable and attempted suicide.

At the age of 43, Mrs. Green was again referred to a mental health care setting for outpatient psychiatric treatment. Quetiapine 600 mg was prescribed and appeared to effectively decrease the headaches, irritability and concentration problems. Overtime and with the aid of her psychiatrist, Mrs. Green developed more self-efficacy skills to cope with the remaining symptoms of DWS. These skills include the identification of sources of stress and the prevention of cognitive overload.

Phase 1: Stabilizing treatment

Diagnostics at the start

After discharge, the psychiatrist who diagnosed Mrs. Greens' symptoms as a Complex PTSD classified the existing co-morbid disorders as follows:

DSM-IV-classification

Axis I: Posttraumatic stress disorder, chronic with associated features
Psychotic disorder related to Dandy Walker Syndrome
Major depressive episode, in remission

Axis II: No diagnosis on Axis II

Axis III: Dandy Walker Syndrome with acquired hydrocephalus

Axis IV: 020 problems in primary support group, 040 working problems, 060 financial problems

Axis V: GAF 45

Based on these diagnoses and after consultation by the FACT-team the treatment plan was modified and aimed at phase-based treatment. Stabilizing interventions were planned at first, and consisted of pharmacotherapy and nursing outreaching care.

Pharmacotherapy

Amitryptyline 50 mg and paracetamol (≤ 4000 mg) were prescribed seven years ago by the neurologist to ease the neuropathic pain that Mrs. Green reported suffering from. Topiramate (50 mg) was prescribed and added three years later to prevent potential epileptic seizures. The quetiapine 600 mg prescribed by the referring psychiatrist four years earlier was also continued in the current treatment context. The psychiatrist now prescribed and added citalopram 40 mg for treatment of the current PTSD related symptoms.

Despite the initial level of mistrust and anxiety on the part of Mrs. Green, the treating psychiatrist was able to build up a therapeutic relationship with her. Mrs. Green also accepted home visits from a mental health nurse.

Outreaching nursing care

Intensive outreach treatment and nursing is an important element of FACT. In the present case, this care was provided on a weekly basis from a visiting home nurse with the following goals in mind: provide support for daily life activities (e.g. self-care, nutrition and housing), reduce avoidance of social activities, and provide tailor-made crisis interventions.

The level of severity of the symptoms and the lack of self-management skills at the time of the FACT nursing intervention, however, impeded positive effects of this outpatient care.

Group stabilizing treatment

Mrs. Green's psychiatrist referred her to the "Before and beyond" stabilizing treatment group. The aims of this treatment are to improve Complex PTSD using psycho-education, emotions regulation skills, social skills, and anxiety-stress management skills in addition to cognitive-behavioral interventions [8, 20].

Measurements for monitoring and evaluation

After enrolment in the stabilizing treatment program, four instruments (e.g., DTS, SIDES, DES, and GAF) were used to measure Complex PTSD symptoms and global functioning before and after Mrs. Green's participation in the stabilizing group treatment and before and after the prolonged exposure treatment (see Table 1).

PTSD symptoms were measured using the Davidson Trauma Scale (DTS). This scale assesses the severity of the DSMI-IV diagnostic criteria for PTSD using 17 well-validated items along a five-point Likert scale. The total scale score can range from 0 to 68. The cut off score is 40 [21].

The presence of a Complex PTSD was confirmed by using the Structured Interview for Disorders of Extreme Stress (SIDES). The SIDES was developed to assess the severity of the following symptom domains of Complex PTSD: affect regulation, memory and attention, self-perception, perception of perpetrator, interpersonal relations, somatization, and systems of meaning. The total SIDES score can range from 0 to 144 [22]. For a diagnosis of Complex PTSD, each domain has to be present except for perception of the perpetrator concluded that the SIDES has sufficient convergent and divergent validity to constitute a valid measure of PTSD with associated features [23]. Scoboria, Ford, Lin and Frisman

(2008) [24] more recently tested the SIDES and showed the derived factors to have good internal consistency [24]. They also found sufficient convergent and discriminant validity.

Table 1. Mrs. Green's clinical diagnoses and symptom course before stabilizing group treatment, after stabilizing grout treatment and after prolonged exposure.

Measure	Baseline *(t=0)*	After stabilizing group treatment *(t=6 months)*	Follow-up and start of prolonged exposure *(t=12 months)*	After prolonged exposure *(t=18 months)*
PTSD diagnosis	Yes	Yes	Yes	No
Complex PTSD diagnosis	Yes	No	No	No
Psychotic symptoms	Yes (mild)	Yes (mild to moderate)	Yes (moderate to severe) [1]	Yes (mild)
Davidson Trauma Scale (DTS, clinician rated)	37	32	-	0
PTSD scale (self-report)			17 [2]	0
Structured Interview for Disorders of Extreme Stress (SIDES)	39 (moderate)	20 (subclinical)	-	1
Dissociative Experiences Scale (DES)	21	43	-	11
Global Assessment of Functioning (GAF)	45	55	-	70

Note: PTSD: Posttraumatic Stress Disorder. [1] During the prolonged exposure period, psychotic symptoms increased and quetiapine doses were upgraded to 1,000 mg. [2] The highest score on PTSD-scale self-report during prolonged exposure was 48 (see Figure 1).

Dissociative features were measured using the Dissociative Experiences Scale (DES). A total of 28 items record the severity of dissociative symptoms. The total score for the DES can range from 0 to100. A total score over 25 suggests a PTSD while a total score over 40 suggests a dissociative disorder [25, 26]. Global functioning including psychological, social, and occupational functioning was measured with the Global Assessment of Functioning (GAF) Scale. This scale considers a hypothetical continuum of mental health illness and does not include impairment in functioning as a result of physical or environmental limitations. It is used for the DSM-IV classification [27].
Psychotic symptoms and medication effects were clinically monitored by the psychiatrist on a monthly base. A validated instrument such as a the Positive and Negative Psychotic Syndrome Scale for Schizophrenia (PANSS) [28] was not used in these evaluations.

The stabilizing group treatment was provided by two therapists: a nurse practitioner (first author) and a clinical nurse specialist. This was done in 20 weekly 2-hour sessions with two follow up sessions after 3 and 6 months according to the protocol. The therapy group consisted of ten members. Mrs. Green appeared to be an active member. She always completed her assignments at home and had positive interactions with other group members. Although she suffered sometimes from headaches and concentration problems, she was never absent. During the group therapy sessions, members were

allowed to leave for a brief “time out”, when feeling overwhelmed. Mrs. Green sometimes left the group on account of irritability problems and twice due to traumatic flashbacks. Active relaxation exercises helped her to calm down and rejoin the group.
During the stabilizing group treatment, positive psychotic symptoms such as hallucinations and delusions did not occur. Negative symptoms such as concentration problems, irritability, and lack of energy increased slightly.
After the stabilizing group treatment, Mrs. Green no longer met the SIDES criteria for Complex PTSD (see table 1). Improvements were seen in terms of self-regulation, assertiveness, and self-esteem. Mrs. Green benefited most from learning the following skills: creation of a ‘safe place’ in her bedroom, relaxation exercises, and correcting thinking errors. As a result of these skills, her self-efficacy also improved. Probably as a result of decreased avoidance, however, she still suffered from intrusions and arousal and thus met the DTS criteria for PTSD (Table 1).
It was expected that the acquired skills and coping strategies would become more effective over time. After multidisciplinary consultation by the FACT-team, it was decided to adopt a watchful waiting policy for a period of six months. Mrs. Green agreed to this.
After this waiting period she functioned better, but still had strong traumatic intrusions. In consultation with her nurse practitioner, the possibility of trauma focused therapy was raised. The FACT-team then extensively considered the potential benefits and risks of such treatment for Mrs. Green. Among the possible benefits were a decrease of the remaining symptoms of PTSD, less suffering, and improved global functioning. Among the possible risks were increased psychotic symptoms without guaranteed reduction of PTSD. The FACT team decided to offer Mrs. Green trauma focused therapy with clear provision of information on the potential benefits and risks and a detailed relapse prevention plan. This plan continued nursing interventions at home and contained crisis management including hospitalization should this prove necessary. Mrs. Green expressed an initial desire to take advantage of this opportunity and, after several shared decision-making steps, she agreed to try trauma focused treatment. Given her neurological problems and because eye movements or auditory stimuli could provoke headaches and convulsions, EMDR was not the preferred option of the trauma focused treatment.

Phase 2: Trauma focused treatment

Prolonged imaginary exposure treatment provided by the already familiar nurse practitioner was decided upon for the trauma focused treatment of Mrs. Green. This was conducted according to the imaginary exposure protocol of [29]. In the first session, psycho-education on the imaginary exposure procedure was provided and agreements were made on the crisis management options and support. The following options were offered in the case of Mrs. Green: low threshold, 24/7 hour telephone access and a psychiatric bed “on call” for unstable nights. These support agreements were formally incorporated into the treatment plan.
During the prolonged exposure intervention phase, symptom severity was assessed at the start of each session using a self-report PTSD-scale. The 17 items constituting this scale are assigned to a score that can range from 0 to 51 with a cut off score of 14 [30] (see Table 1 and Figure 1).
A tentative fear hierarchy including all known traumatic events for Mrs. Green was next composed in collaboration with Mrs. Green. The following list was then agreed upon: sudden loss of partner, emotional neglect and abuse by mother, forced assistance of father in beating of her sister, sexual abuse by a relative, and sexual abuse by father. In sessions two through six, these traumatic events

were consecutively recalled. In session six, memories of the involvement of both parents in sexual invasive abuse of Mrs. Green in early childhood were also recovered.

Exposure had to be interrupted in session seven when high levels of anxiety occurred. Mrs. Green was also quite sad about the past behavior or her parents. Using a genogram to talk about positive experiences with her extended family appeared to provide support and ease her grief to some extent. Session eight consisted of stabilizing interventions aimed at reducing anxiety and promoting safety with the use of an "on call" psychiatric bed.

In session nine, Mrs. Green mentioned that new memories had been recovered about another abusing relative but that she did not dare to talk about it. The week after this session, she developed psychotic symptoms when at home (e.g., visual hallucinations in the form of seeing flying bats and deformations of objects; auditory hallucinations in the form of hearing her dead dog barking); she also experienced increased dissociative features (e.g., derealization and depersonalization). The quetiapine dosage was increased to 1000 mg by her psychiatrist.

After multidisciplinary consultation, continuation of the exposure sessions in a clinical setting was offered and Mrs. Green agreed to this. While waiting for admission, the session on the early sexual abuse by her father was repeated in detail and an extended genogram was created in another session to provide support (see Figure 1, session topics).

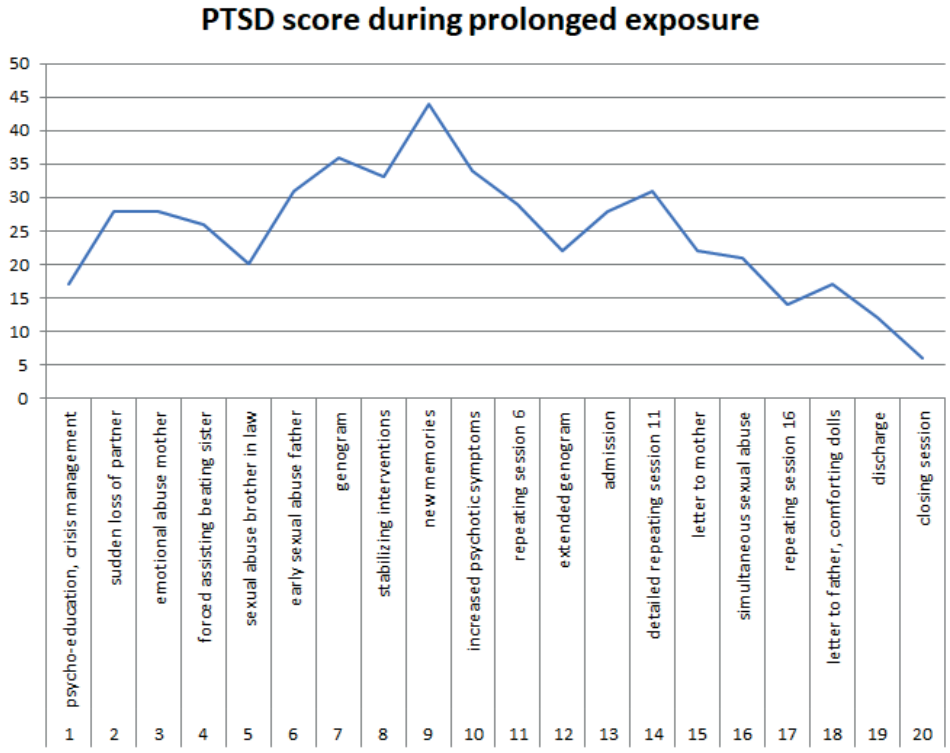

Figure 1. Self-reported posttraumatic stress disorder (PTSD) symptom score at the start of each session. The numbers correspond with each weekly session.

Upon admission, exposure continued. Mrs. Green wrote a letter to her mother during this episode and in session 15, she read the letter out loud. In session 16, the most frightening memories – the recently recovered memories of the involvement of both parents in early sexually invasive abuse of Mrs. Green and abuse by another relative - were told. This session was repeated in detail during session 17.
Mrs. Green wrote a letter to her father and read it out loud in session 18. After this she felt very relieved because her fear was now gone. She was also very sad and talked about the little girl she had been and how she longed to comfort that little girl. A woman doll and a child doll were then given to her to depict the comforting that she longed for when she was a little child, but did not receive then.
Mrs. Green was given a great deal of support by the nurses on the ward. They played a key role in helping her cope with her fear and sadness. For example, some nurses sat together with her when she listened to the audiotapes of the sessions, which she did on a regular basis following the protocol.
After the completion of 18 exposure sessions, Mrs. Green returned home. In session 19, a closing ritual was prepared. Mrs. Green broke the CD with the audiotaped sessions sixteen and seventeen on it. She then buried it near her parents' burial place with her therapist present to witness the event and provide support.

Phase 3: Integration and recovery of connection

Shortly after the closing therapy session, Mrs. Green no longer met the criteria for Complex PTSD and the dissociative experiences were almost gone. Her global functioning, according to the GAF, had further improved (see Table 1). She no longer had a need for intensive psychiatric home care. She reported experiencing a great relief and talked about feeling overjoyed.
At this point, further recovery-based treatment was offered to Mrs. Green, but she said that she preferred to enjoy her "new life" for a while and to simply use her prophylactic medication. Six months later she suffered from new memories about another abusing relative. Two exposure sessions were provided to process these memories. Her flashbacks and feelings of fear disappeared after these sessions.

Pharmacotherapy
Mrs. Green had numerous medications for co-morbid neurological and psychiatric symptoms. Reducing polypharmacy was thus an important goal for the promotion of further recovery. First, the quetiapine dosage (1000 mg) was reduced by 50 mg per week to 600 mg. A dosage lower than 400 mg gave rise to neurological problems and therefore a dosage of 600 mg was continued. The dosage of citalopram 40 mg was next reduced by 10 mg per week and finally stopped.
Mrs. Green mentioned feeling better then: more energetic and much less sedated. Hallucinations and delusions did not occur in this period. Negative symptoms such as concentration problems and lack of energy - which were hardly to distinguish from neurological symptoms or side-effects of quetiapine – improved: her concentration improved and her daily life became more active.

Lifestyle interventions
Mrs. Green had become overweight over time, probably due to huge calorie intake which is associated with high quetiapine doses and a lack of physical exercise as a result of avoiding many activities in the past. Somatic screening for side effects of medication was therefore conducted in line with the Dutch national guidelines for psychosis treatment [31]. The screening results showed small changes in

glucose and lipid laboratory values. Medical policy therefore called for further reduction of polypharmacy, a low-calorie diet, and supporting a healthy lifestyle.
As Mrs. Green regained her self-confidence and became more active, she also got involved in sports and became more physically active on a day-to-day basis with walking and cycling. She visited a dietician for advice and joined a lifestyle training program at the mental health center.

Social contact and activities
Regaining meaningful social contacts was stimulated with the training of social skills. This helped Mrs. Green establish healthy boundaries with significant others. She demonstrated more initiative for social contact and reported enjoying these experiences. She visited her youngest aunt, who had been very nice to her in the past. This aunt offered her a broader perspective on her parents and is now an important relative.
Mrs. Green is currently helping elderly people in a nursing home on a voluntary basis. She reports a markedly better quality of life after a long and challenging recovery process.

3.4 DISCUSSION

Stabilization
Patients with severe mental illness such as psychotic disorders and co-morbid Complex or chronic PTSD can be treated successfully with interventions aimed at stabilization. These interventions can consist of: emotion regulation strategies; anxiety and stress management; cognitive restructuring; and enhancement of interpersonal skills. Complex PTSD symptoms have been shown to decrease or disappear following such interventions [8, 32].
The remaining symptoms can be persistent, however, and sometimes complicate further recovery. In the present case of a Complex PTSD, many symptoms decreased significantly following stabilizing group treatment. The regulation of emotion, social skills, and trust all improved while anxiety and stress were better tolerated. Existing negative psychotic symptoms (e.g. concentration problems and lack of energy) increased slightly, but this increase did not interfere with the stabilizing process in the case of Mrs. Green: avoidance decreased while intrusions and arousal persisted.
Given that learned skills can improve over time and symptoms further decrease over time, we decided to wait six months and then re-assess Mrs. Green's symptoms. In hindsight and given the level of patient suffering, this period could have been shorter. However, Mrs. Green thought she needed this time to make up her mind with regard to trying trauma focused therapy.

Trauma focused therapy: prolonged exposure
Prolonged imaginary exposure treatment provided by the already familiar nurse practitioner was decided upon for the trauma-focused treatment of Mrs. Green. This was conducted according to the imaginary exposure protocol of Foa, Hembree, and Rothbaum [29].
However, co-morbid psychosis is a potential contraindication for trauma focused therapy because of the risk of increasing psychotic symptoms. After multidisciplinary consultation among the care professionals, the potential advantages and disadvantages of prolonged exposure were extensively discussed with the patient who then decided to try this treatment.
Important factors influencing the decision to try exposure were the ongoing clear and continued contact with the psychiatrist and visiting nurse; daily activities in a protected environment; a positive

therapeutic relationship with the nurse practitioner since the initiation of stabilizing treatment; and the possibility for hospital admission when necessary. This treatment approach is in line with the findings in other studies showing prolonged exposure to be effective for the treatment of PTSD in patients with co-morbid psychosis.

In a recent review of potential contraindications for the use of prolonged exposure therapy in cases of PTSD, psychosis was not found to constitute a contraindication [33]. This conclusion is based on the positive effects of prolonged exposure on both the symptoms of PTSD and psychotic symptoms. The authors of the review nevertheless emphasize that the following conditions must be in place: concurrent care as usual, including pharmacotherapy, case management, and the formulation of a crisis intervention plan. In the present case of PTSD with co-morbid psychosis, positive psychotic symptoms consisting of visual and auditory hallucinations not related to traumatic memories, occurred during prolonged exposure but disappeared after the PTSD went in remission. The negative symptoms improved slightly but concentration problems and irritability which are also related to DWS remained. Pharmacological treatment and crisis intervention in the form of hospital admission further appeared to be effective for helping the patient endure the prolonged exposure.

Integration and recovery of connection

Integration of traumatic memories was associated with the mourning of the loss of her family members. Writing letters to her abusive but now deceased parents helped the patient in our study to cope with her traumatic past and a closing ritual helped to finalize this.

Recovery of connection is an important part of the third phase in the phase-based treatment of Complex PTSD [6]. In the present case, recovery of connection with a relative appeared to be critical and took the form of renewed contact with a non-abusive aunt. Her work as a volunteer with elderly people also gave her a significant experience of connection.

Mrs. Green's general recovery was also promoted by the stimulation of a healthier lifestyle and by the reduction of polypharmacy with the associated side effects of such heavy medication. The integrated care offered by the nurse practitioner may have resulted in more attention to her physical health and the interaction with mental health problems and wellbeing.

Collaborative care

The multidisciplinary treatment approach adopted for the complex case reported on here, appeared to be critical and in line with the conditions recently outlined for the treatment of PTSD using prolonged exposure [33]. Several team members formed a safety net for this socially isolated patient, which she experienced as crucial for gaining her trust and helping her cope with the traumatic memories and feelings.

The provision of such clinical conditions may not always be possible, however. It is therefore recommended that the therapist work together with at least a second therapist for the provision – for example – of pharmacotherapy and crisis management. It is also recommended that the therapist work with a significant other (i.e., relative or friend of the patient) to guarantee daily support for the patient whenever necessary.

Aftercare

This patient in the present study needed aftercare for remaining psychotic symptoms associated with the DWS. In stable phases of her illness, pharmacological treatment under the guidance of a psychiatrist will still be necessary.

Steps for the prevention of psychotic relapse when stress or signs of relapse present themselves must also be established. A plan to be followed should be formulated with detailed descriptions of the early symptoms of (increasing) psychosis and possible neurological symptoms such as headaches, irritability, and problems with movement coordination. The relapse prevention plan provides information about the support and availability of other involved professionals (general practitioner, neurologist).

3.5 LIMITATIONS AND CAVEATS

The psychosis of the patient described in the present case study stemmed from the DWS and thus had an organic nature. This could limit the generalizability of the phase-based treatment protocol described here to the treatment of patients with so-called functional psychosis. However, the similarities with schizophrenia are such that in clinical practice, treatment of the co-morbid psychotic symptoms was comparable in terms of pharmacotherapy, psycho-education and relapse prevention. Psychotic symptoms were evaluated clinically in the present study and thus not monitored using a validated structured interview such as the PANSS [28].

3.6 CONCLUSION

This case report shows effective treatment of a Complex PTSD with severe psychiatric and somatic co-morbidity to be possible. A number of factors can be seen to be of importance: (1) Broadly based treatment policy with the inclusion of a FACT-team and adequate cooperation between care professionals (e.g., psychiatrists, neurologists, nurses, and nurse practitioners). (2) Adoption of phase-based treatment to deal with the Complex PTSD. (3) Use of clear protocols for stabilization, stabilizing group treatment, and prolonged exposure procedure. (4) Flexibility in the form of well-considered and clearly justified deviation from protocols when required or deemed necessary. (5) Clearly articulated and agreed-upon plans for crisis management and support. (6) Shared decision-making with the client during all phases of therapy and customization of the treatment were also seen to be very important for the therapeutic process as these helped create trust and foster a sense of mastery on the part of the client. (7) And last but not least, a very motivated and brave client.
Further exploring the present treatment model is recommended for patients with a Complex PTSD and co-morbid psychosis or another severe mental illness. Depending on the configuration of individual case and illness characteristics, treatment phases may need to be made shorter or longer to allow – for instance – less time between stabilization and the start of trauma focused therapy [3, 34]. The provision of intensive psychotherapy (i.e., stabilizing group treatment followed by trauma focused therapy) for patients with severe mental illness and co-morbid Complex PTSD may, moreover, be promising from an economic perspective. That is, a temporary increase of costs can lead to lower health care costs in the long run and improved social participation. In the present case the benefits clearly outweighed the costs.

Patient informed consent and privacy protection
This patient has given written informed consent for the publication. Her identity has been disguised by omission and alteration of non-crucial information.

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“A good beginning makes a good ending”

South English Legendary, 1300

Chapter 4

Narrative Exposure Therapy for Posttraumatic Stress Disorder associated with repeated interpersonal trauma in patients with Severe Mental Illness: a mixed methods design

Study protocol

Maria Mauritz

Betsie van Gaal

Ruud Jongedijk

Lisette Schoonhoven

Maria Nijhuis-van der Sanden

Peter Goossens

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ABSTRACT

Background: In the Netherlands, most patients with Severe Mental Illness (SMI) receive Flexible Assertive Community Treatment (FACT) provided by multidisciplinary community mental health teams. SMI patients with comorbid Posttraumatic Stress disorder (PTSD) are sometimes offered evidence based trauma focused treatment like Eye Movement Desensitization Reprocessing or Prolonged Exposure. There is a large amount of evidence for the effectiveness of Narrative Exposure Therapy (NET) within various vulnerable patient groups with repeated interpersonal trauma. Some FACT-teams provide NET for patients with comorbid PTSD, which is promising, but has not been specifically studied in SMI patients.

Objectives: The primary aim is to evaluate NET in SMI patients with comorbid PTSD associated with repeated interpersonal trauma whether**:** a) PTSD and dissociative symptoms changes and b) changes occur in the present SMI symptoms, care needs, quality of life, global functioning, and care consumption. The second aim is to gain insight in patients' experiences with NET and to identify influencing factors on treatment results.

Methods: This study will have a mixed methods convergent design consisting of quantitative repeated measures and qualitative semi-structured in-depth interviews based on Grounded Theory. The study population will include adult SMI outpatients (n=25) with comorbid PTSD and receiving NET. The *quantitative* study parameters will be: existence and severity of PTSD, dissociative, and SMI symptoms; care needs; quality of life; global functioning; and care consumption. Outcomes will be analysed using mixed models to estimate the difference in means between baseline and repeated follow up measurements. The q*ualitative* study parameters will be: experiences with NET and perceived factors for success or failure. *Integration* of quantitative and qualitative results will be focused on interpreting how qualitative results enhance the understanding of quantitative outcomes.

Discussion: The results of this study will provide more insight into influencing factors for clinical changes in this population.

Keywords: Physical abuse, sexual abuse, posttraumatic stress disorder, schizophrenia, mood disorder, personality disorder, flexible assertive community treatment, mixed methods, repeated measures, in-depth interview.

Highlights of the article

- Nearly fifty percent of severely mentally ill (SMI) patients has been exposed to repeated violence and thirty percent is suffering from PTSD
- Narrative Exposure Therapy (NET) is designed for PTSD related to repeated trauma and proved effective in refugees and other vulnerable patient groups
- NET is provided to SMI patients with PTSD and the first clinical outcomes are promising
- This study will analyse symptom changes after NET in relation to patients' experiences with this treatment

4.1 BACKGROUND

Despite the large attention in research for trauma and posttraumatic stress disorder (PTSD), the interest in the prevalence and treatment options for trauma and PTSD in severely mentally ill (SMI) populations is scarce, albeit growing. Research results show that documentation of trauma and trauma symptoms is exceptionally low in medical records of SMI patients. Improved recognition is needed to provide adequate treatment and meaningful services to this vulnerable population [1-5]. In a recently conducted review on trauma and PTSD in SMI, the population weighted mean prevalence rates are respectively: physical abuse 47%, sexual abuse 37%, and PTSD 30% [6]. These prevalence rates are significantly higher than in the general population where the prevalence of physical abuse is 21%, sexual abuse 23% [7] and the lifetime prevalence of PTSD is estimated to be 6.8% among adult Americans [8, 9] and 7.4% in de Netherlands [10].

Repeated interpersonal trauma such as physical and sexual abuse may result in PTSD with dissociative symptoms which is classified as PTSD, dissociative subtype in DSM-5 [11]. Interpersonal trauma and comorbid PTSD both have a negative influence on the course of the SMI [6]. Trauma exposure itself is strongly related to several other psychiatric disorders. Childhood trauma, for instance, is identified as a causal factor in the development of psychotic disorders [12].

It is also shown that PTSD in patients with SMI can be treated effectively using the following treatment options: cognitive restructuring [13, 14], prolonged exposure (PE) [15, 16] or Eye Movement Desensitization Reprocessing (EMDR) [17]. In a recently conducted randomized controlled trial, both PE and EMDR treatment appeared effective, safe, and feasible in patients with severe psychotic disorders and comorbid PTSD [18].

Narrative exposure therapy (NET) is a relatively new trauma-focused treatment. It has been shown effective in vulnerable groups like refugees and other patients with a history of repeated trauma exposure including patients with borderline personality disorder (BPD) or major depression and comorbid PTSD.

NET appeared to be well tolerated in these groups in these groups [19-23]. NET is indicated for PTSD as a result of repeated trauma, usually as a result of interpersonal violence.

4.2 OBJECTIVES

The primary aim of this study is to evaluate NET in SMI patients with comorbid PTSD associated with repeated interpersonal trauma to get insight whether: a) the PTSD and present dissociative symptoms changes and b) changes occur in the present SMI symptoms, care needs, quality of life, global functioning, and care consumption. The second aim is to gain insight in patients' experiences with NET and to identify influencing factors on treatment results in terms of symptom changes, care needs, and quality of life.

4.3 METHODS

This study uses a mixed methods convergent design: a quantitative repeated measures design and qualitative methods consisting of a Grounded Theory design. The aim of a mixed methods design is to integrate quantitative and qualitative components to obtain additional knowledge [24, 25]. In this study integration will be focused on interpreting how qualitative outcomes regarding patients' experiences with NET enhance the understanding of the quantitative clinical outcomes.

Study population

The study population consists of adult (age 21 to 65 years) SMI patients receiving Flexible Assertive Community Treatment (FACT). SMI is defined as the presence of schizophrenia-spectrum disorder, mood disorder, or personality disorder and decreased global functioning which is operationalized by a Global Assessment of Functioning (GAF)-score < 60 during two or more years [6, 26, 27].

FACT includes coordinated multidisciplinary treatment (i.e. pharmacotherapy, cognitive behavioral therapy, and other relevant evidence based interventions) and collaborative care (i.e. case management and nursing care) for patients in a stable phase. Unstable patients receive intensive assertive outreaching care delivered by more team members according to the principle of shared caseload [28, 29].

Patients with a history of repeated interpersonal trauma (physical and/or sexual abuse) and with comorbid PTSD are offered NET by trained FACT-team therapists. Participants will be recruited from all FACT-teams from ten community mental health teams at a large mental health institute in the East-Netherlands. Inclusion will start at the beginning of 2016 and will last to the end of 2017.

Potential participants will obtain oral and written information about the study from their treating psychiatrist and the primary investigator. They will be asked to sign an informed consent form if they are willing to participate.

Inclusion criteria

In order to be eligible to participate in this study, a patient must meet the following criteria for the existence of: 1) SMI: a diagnosis of schizophrenia (DSM-5 295.90), or schizoaffective disorder (DSM-5 295.70) bipolar disorder type I (DSM-5 296.40-46 or 296.50-56) or type II (DSM-5 296.89), or major depressive disorder (DSM-5 296.20-26 or 296.30-36) [11] according to the Mini-International Neuropsychiatric Interview (M.I.N.I.-plus) [30] or personality disorder (DSM 5 301.xx) according to the Structured Clinical Interview for DSM-IV Personality Disorders SCID-II [31] and each has a GAF-score [32] (APA, 2000) < 60 during ≥ two years according to the chart diagnosis, 2) a trauma history including repeated physical and/or sexual abuse according to the Life Events Checklist for DSM-5 (LEC-5) [33], and 3) PTSD according the Clinician-Administered PTSD Scale for DSM-5 (CAPS-5) [34].

Exclusion criteria

A potential patient who meets any of the following criteria will be excluded from participation in this study: 1) the provision of other trauma focused treatment in the past year, 2) the existence of an antisocial personality disorder, 3) the existence of a dissociative identity disorder, and, 4) the provision of involuntary treatment following the Dutch Mental Health Law**.**

Sample size

We expect to be able to include 25 participants within two years. This number of participants will possibly be sufficient to demonstrate potential changes on quantitative outcomes. For qualitative analysis the number of 25 participants is sufficient.

Treatment with Narrative Exposure Therapy (NET)

Schauer, Neuner and Elbert (2011) [35] describe the proved effective main elements of NET as follows: (1) an active chronological reconstruction of the autobiographical memory, (2) prolonged exposure to the traumatic memory with full activation of the emotional fear network through detailed narration and imagination of the traumatic event, (3) meaningful linkage and integration of physiological, sensory, cognitive, and emotional responses to the persons time, space, and life context, (4) cognitive re-evaluation of behaviour and patterns, reinterpretation of the meaning content through reprocessing of fearful and traumatic events, with completion and closure, (5) revisiting of positive life experiences, and (6) regaining of dignity through satisfaction of the need for acknowledgment through "testifying" [35, 36].

The provision of NET is outlined as follows: session 1: psycho-education, session 2: the lifeline which is symbolized by a rope with a coiled end, stones (traumatic events) and flowers (positive life experiences) in time sequences, session 3: start of the narration beginning at birth and continuing through to the first traumatic event, session 4 and subsequent sessions rereading of the narrative collected in previous sessions, continuing the narration of subsequent life and traumatic events, final session: rereading en signing the whole document. The average number of the weekly 90-minute sessions varies from six to sixteen [36-38]. NET is provided by both nurse practitioners and psychologists who are all thoroughly trained by official qualified and certified trainers and who receive video supervision by a certified psychologist or nurse practitioner.

Data collection

Quantitative measurements

Patients will participate in the study for ten months. At pre-treatment (T0) a trained and supervised research assistant will collect demographic information from the electronic record and assess baseline measurements of all variables. These variables include: trauma history, PTSD diagnosis and symptoms, dissociative symptoms, SMI diagnosis and symptoms, care needs, quality of life and global functioning. At post-treatment one month after NET (T1) and after seven months follow up (T2) clinical outcomes including PTSD symptoms, dissociative symptoms, SMI symptoms, care needs, quality of life and global functioning are assessed again (see table 1).

Care consumption and prescribed psychiatric medications will be collected via the electronic record. These data will be analyzed for the following period: three months before T0 up to and including T2.

Table 1. Measurements in scheme.

	T0. Inclusion and before intervention	*T1. 1 month after finalizing intervention*	*T2. 7 months follow-up*
Demographics	Collected via the electronic record	--	--
Care consumption [1]	Continuously collected via the electronic record		
Trauma history	LEC-5		
PTSD symptoms	CAPS-5	CAPS-5	CAPS-5
Dissociative symptoms	DES	DES	DES
SMI diagnosis	M.I.N.I.-plus or SCID-II	--	--
SMI symptoms	HoNOS	HoNOS	HoNOS
Care needs	CAN	CAN	CAN
Quality of life	MANSA	MANSA	MANSA
Global functioning	GAF	GAF	GAF

[1] management and medication information

Demographic information

Demographic variables include: gender, age, marital status, level of completed education, number and duration of traumatic event types (emotional, physical, and/or sexual abuse in childhood and/or adulthood), primary SMI diagnosis, duration of illness, prescribed medication and experiences with forced hospitalization and seclusion. These variables are largely collected via the electronic record and based on the inclusion interview outcomes.

Care consumption

Care consumption is defined as the number and time duration in minutes of contacts with FACT-team members and prescribed psychiatric medications (type and doses).

Instruments

Life Events Checklist for DSM-5 (LEC-5)

The LEC is developed concurrently with the Clinician-Administered PTSD Scale (CAPS) to facilitate the diagnosis of PTSD and is a measure of exposure to 17 potentially traumatic events. The LEC is evaluated in college undergraduates and combat veterans by [39]. In this study the LEC had temporal stability, convergent validity and was strongly associated with PTSD symptoms in a clinical sample. The LEC-5

connects to the CAPS-5 and has some minimal changes compared with the original LEC [40]. The LEC-5 will be administered after positive screening for repeated trauma exposure on the Trauma Screening Questionnaire (TSQ) [41, 42] and PTSD on the PTSD checklist for the DSM-5 (PCL-5) [43, 44]. The Dutch version of the LEC-5 will be used in this study [33].

Dissociative Experiences Scale

Dissociative symptoms are measured using the Dissociative Experiences Scale (DES) which consists of 28 items and record the severity of dissociative symptoms. The total score for the DES can range from 0 to 100. A total score over 25 suggests a PTSD while a total score over 40 suggests a dissociative disorder [45, 46]. The Dutch version of the DES discriminate dissociative disorders from other psychiatric disorders and appeared a reliable and valid instrument [47, 48].

Table 2. The mixed methods convergent design in scheme.

Months	0	1	2	3	4	5	6	7	8	9	10
		<------ NET ------>			<---------- Follow-up ---------->						
Data collection	T0				T1			Int.			T2
Quantitative: Measurements	■				■						■
Qualitative: Semi-structured interviews (Int.)								■			

Clinician-Administered PTSD Scale for DSM-5 (CAPS-5)

The CAPS is a structured diagnostic interview designed for PTSD according DSM-IV [49]. The CAPS is considered as the gold standard clinical interview to establish the diagnosis PTSD. The CAPS-5 is based on the original CAPS for DSM-IV but has several important revisions based on the corresponding DSM-5 criteria for PTSD. This 30-item structured interview can be used to make current (past month) and lifetime diagnosis of PTSD and assess PTSD symptoms over the past week [50]. The Dutch version of the CAPS-5 will be used [34].

Mini-International Neuropsychiatric Interview (M.I.N.I.-plus)

The M.I.N.I.-plus is a short structured diagnostic interview, developed jointly by psychiatrists and clinicians in the United States and Europe, for DSM-IV and ICD-10 psychiatric disorders. The M.I.N.I.-plus was designed as a brief structured interview for the major Axis I psychiatric disorders in DSM-IV and ICD-10. Validation and reliability studies show that the M.I.N.I.-plus has acceptably high validation and reliability scores and can be administered in a short period of time (mean 18.7 ± 11.6 minutes, median 15 minutes). It can be used by clinicians after a brief training session [30].

The Dutch version of the M.I.N.I.-plus is tested in a selected group of Dutch psychiatric patients. Based on initial experiences and results, van Vliet & de Beurs (2007) [51] conclude that the good psychometric characteristics of the M.I.N.I.-plus make it a good choice for research purposes. Because of its brevity (20-30 minutes) the interview seems to be especially convenient for diagnosing psychiatric patients in everyday clinical practice [51].

Structured Clinical Interview for DSM-IV Personality Disorders (SCID-II)
The SCID-II is a clinician-administered semi-structured interview for diagnosing the Axis II personality disorders of the DSM-III-R. Is was designed to provide a rapid clinical assessment of personality disorders without the loss of reliability or validity [52]**.** After the publication of the DSM-IV in 1994, the SCID-II has been revised to meet the DSM-IV criteria (SCID-II version 2.0). Maffei et al. (1997) [53] assessed the interrater reliability and internal consistency of the SCID-II 2.0 and concluded that this version of the SCID-II has adequate interrater and internal consistency reliability [53]. In the Netherlands the reliability of the Dutch version of the SCID-II was further investigated with regard to the test-retest interrater reliability. Test-retest interrater reliability for the presence or absence of any personality disorder was fair to good and was higher than values found in previous short-interval test-retest studies with the SCID-II for DSM-III-R [54].

Health of the Nation Outcome Scale (HoNOS)
The health of the Nation Outcome Scale (HoNOS) has been developed for assessing the effectiveness of mental health services for patients with severe mental illness. It covers a wide range of areas and has good criterion- and concurrent validity [55]. Rees, Richards & Shapiro (2004) [56] assessed the usefulness of the HoNOS in measuring change in a community mental health population and concluded that a change of 3 to 4 points was statistically significant and useful for tracking clinical improvement [56]. The Dutch translation of the HoNOS has been studied and provided insight at both individual and group level into the seriousness of problems and into occurred changes. It has reasonably good psychometric qualities, can be administrated in a short time, and is not dependent on psychiatric diagnosis or language and useful by both clinicians and patients [57].

Camberwell Assessment of Needs (CAN)
The CAN is commonly used for comprehensive needs assessment in mental health services. It is a valid, reliable and usable measuring instrument to assess the care need of SMI patients [58]. Wennström, Sorbom and Wiesel (2004) [59] concluded after exploratory factor analysis that the CAN represents three homogeneous dimensions: functional disability, social loneliness and emotional loneliness. The summary scores of items corresponding to functional disability and social health might more reliable and more sensitive to changes over time than the standard Camberwell Assessment of Need (CAN) summary scores [59].

Manchester Short Assessment of quality of life (MANSA)
The MANSA is a short instrument for assessing quality of life in people with mental illness. This instrument measures satisfaction of life as a whole and with life domains [60]. The MANSA was examined with regard to reliability and construct validity in patients with SMI. Internal consistency was adequate (alpha = 0.81). The construct validity of the scale was satisfactory in this study [61].

Global Assessment of Functioning (GAF) Scale
The GAF Scale measures psychological, social, and occupational functioning. This scale considers a hypothetical continuum of mental health illness and does not include impairment in functioning as a result of physical or environmental limitations. It is used for the DSM-IV classification [32].

Qualitative semi structured interviews

To investigate participants' experiences with NET and to identify possible influencing factors for success or failure of NET, participants will be interviewed. Sensitizing concepts are: 1) experiences during NET, 2) symptom changes, 3) care needs, 4) quality of life and daily life functioning, and 5) influencing factors and meaning. Based on these concepts the following topics are derived and listed: ad 1: therapeutic relationship, lifeline, narration, exposure, and the treatment effects in daily life, ad 2: experienced symptoms, ad 3: perceived care needs, ad 4: perceived quality of life and effects on daily functioning, and ad 5: experienced success or failure and significance for meaningfulness in daily life (see supplement 1).

The interviews will be held three months after finalising NET (see table 2). The maximum length of the interviews will be 60 minutes. One independent researcher (first author) will interview all participants. Interviews will be audiotaped and typed out verbatim. The interviewer will be blinded for measurement results to provide a neutral attitude and prevent bias based on foreknowledge. Interviews will be held on the known FACT location or at the patient's home. Participants can stop the interview at any moment. The audio files and written content of the interview results are confidential.

4.4 ANALYSIS

Quantitative analysis

Descriptive analysis will be used to describe the patient characteristics and the repeated measures outcomes. To analyse the clinical outcomes of the NET, mixed models will be used to estimate the difference in means between outcomes, taken into account the repeated measures.

Qualitative analysis

The qualitative data analysis forms a cyclic process, with the interim analyses modifying subsequent interviews. This procedure is well known as the constant comparative method. The texts of the interviews will be transcribed literally and then entered in the ATLAS.ti computer program for qualitative text analysis [62]. Then will be started with open coding: small text fragments will be labelled. This label or code has a descriptive nature and closely follows the text. At the same time questions and remarks about ambiguities in the text or possible interpretations will be described in brief notes. The next analysis stage will exists of joining the small text fragments without losing the original codes and labelling these fragments with a higher level of abstraction. These codes will not only be descriptive but also interpretative. During this process the similarities and differences between interviews will be explored according to the principles of the constant comparative analysis. During the third analysis stage text fragments will be further joined, categorized, and described. These categories will reflect the dominant themes and possible relevant determinants. The first three interviews will be independently coded by two researchers.

Methodological objectivity

The methodological objectivity will be enhanced by: (a) purposive sampling confined to SMI patients who have recently received NET treatment for comorbid PTSD, (b) a neutral attitude in asking questions and in orally checking the findings with the respondent, (c) researcher triangulation: minimization of researcher bias by independent coding and analysing interviews by two researchers,

(d) member check in order to assess the accuracy of the representation of the participant's subjectivity, (e) peer debriefing with the whole research group during data collection and analysis, (f) peer debriefing with two independent NET therapists and two FACT-team members who care for the participants, (g) transparency and reproducibility through careful documentation of all steps of the research process. Interviews are tape recorded and verbatim transcribed. The raw material is saved and stored in its entirety to be available for verification purposes.

Integrated analysis

Integration of both quantitative and qualitative results will be focused on interpreting how the qualitative results enhance the understanding of the quantitative outcomes.

Ethics

The study will be conducted with ethical principles that are consistent with the Declaration of Helsinki, amended by the *59th WMA General Assembly, Seoul, October 2008.* The ethical approval for conducting the "NET for PTSD in SMI patients" study was provided by the Committee on Research Involving Human Subjects, Arnhem-Nijmegen (number 1843-2015).

4.4 DISCUSSION

NET has shown to be effective in vulnerable groups and first clinical results in SMI patients with comorbid PTSD receiving FACT have been promising. To evaluate and improve clinical practice, only relying on quantitative measures might not suffice as it lacks sensitivity for this specific population. Moreover, the mixed methods approach further enriches the quantitative data with qualitative interviews addressing patients' perspectives on effectiveness, barriers and facilitating factors.

Registration

This study protocol is registered in The Netherlands National Trial Register (NTR) number NTR5714.

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Supplement 1. Topic list of semi-structured interview

The topics are derived from the sensitizing concepts and arranged by each concept

*Experiences **during** NET*

- Therapeutic relationship
- Lifeline
- Narration
- Exposure
- Treatment effects in daily life

*Experienced severity of symptoms **before, during and after** NET*

For instance:

- Intrusion
- Avoidance
- Negative alterations in cognitions and mood
- Alterations in arousal and reactivity
- Depersonalization and derealisation
- Symptoms of present psychotic, bipolar, depressive or personality disorder
- Suicidality

Changes in care needs

- perceived decreased care needs (which areas of life)
- perceived persisting care needs (which areas of life)

Changes in quality of life

- perceived quality of life (which aspects)
- perceived effects on daily life functioning

Experienced success of failure and meaning

- success (example)
- failure (example)
- significance for meaningfulness

“While trauma keeps us dumbfounded, the path out of it is paved with words, carefully assembled, piece by piece, until the whole story can be revealed”

Bessel van der Kolk, The body keeps the score.
Mind, brain and body in the transformation of trauma, 2014

Chapter 5

Treating patients with severe mentally illness with narrative exposure therapy for comorbid post-traumatic stress disorder

Maria Mauritz

Betsie van Gaal

Peter Goossens

Ruud Jongedijk

Hester Vermeulen

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ABSTRACT

Background: Interpersonal trauma and post-traumatic stress disorder (PTSD) in patients with severe mental illness (SMI) negatively affect illness course. Narrative exposure therapy (NET) is effective in vulnerable patient groups, but its efficacy and applicability has not been studied in outpatients with SMI.

Aims: We aimed to evaluate the efficacy and applicability of NET in SMI on changes in PTSD, dissociation, SMI symptoms, care needs, quality of life, global functioning and care consumption.

Method: The study had a single-group, pre-test–post-test, repeated measures design and was registered in The Netherlands National Trial Register (identifier TR571). Primary outcomes were assessed at pre-treatment (T0), 1 month post-treatment (T1) and 7 months' follow-up (T2), with a structured interview for PTSD and dissociation screening. Secondary outcomes followed routinely SMI measurements and medical data. Mixed models were used for data analysis.

Results: The majority of the 23 participants was female (82%). Mean age was 49.9 years (s.d. 9.8) and mean PTSD duration was 24.1 years (s.d. 14.5). Mean PTSD severity decreased from 37.9 at T0 to 31.9 at T1 (−6.0 difference, 95%CI −10.0 to −2.0), and decreased further to 24.5 at T2 (−13.4 difference, 95%CI −17.4 to −9.4). Dissociation, SMI symptoms, duration of contacts, and medication decreased; global functioning increased; and quality of life and perceived needs did not change. Eleven participants were in remission for PTSD at T2, of which five were also in remission for major depression

Conclusions: NET appeared efficacious and applicable to outpatients with SMI and PTSD, and was well tolerated.

Keywords: post-traumatic stress disorder; severe mental illness; narrative exposure therapy; single group; repeated-measures.

5.1 INTRODUCTION

In the last decade, the high prevalence of interpersonal trauma and Posttraumatic Stress Disorder (PTSD) in patients with severe mental illness (SMI) has received considerable attention. Trauma and PTSD are still underdiagnosed in SMI-patients and have a negative influence on the illness course [1-3], specifically for psychotic disorders [4], bipolar disorders [5], and major depressive disorders [6]. That is why clinicians and researchers emphasize the importance of adequate screening for trauma and PTSD to counteract under-treatment in this vulnerable population [7]. Controlled intervention studies have shown that PTSD in SMI patients can be treated effectively by the following trauma focussed treatment (TFT) options: cognitive behavioural treatment (CBT), prolonged exposure (PE) and Eye Movement Desensitization Reprocessing (EMDR) [8-12]. An alternative TFT is Narrative Exposure Therapy (NET) for patients who are exposed to repeated traumatic events during their life cycle. NET integrates prolonged exposure into the life story and includes attention to positive meaningful events [13, 14]. NET has been proven effective in particular in vulnerable patient groups like refugees [15, 16] and patients with a history of interpersonal trauma including child and adult abuse [17]. At this moment, NET has not yet been studied in SMI patients receiving community mental health care**.** Therefore, to underpin the use of NET in clinical practice, this study evaluates the efficacy and applicability of NET in SMI outpatients with comorbid PTSD associated with repeated interpersonal trauma.

5.2. METHOD

Design

This study was a single group pre-test-post-test study with repeated-measures and was part of a larger mixed methods study [14, 18]. The study was registered in The Netherlands National Trial Register (ID: TR5714) [19].

Ethics statement

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving patients were approved by the Committee on Research Involving Human Subjects Arnhem-Nijmegen provided ethical approval (number 1843-2015) [14] of the study. The study started in April 2016 and ended in January 2019.

Participants

We included adult (age 21-65 years) outpatients with SMI and a history of repeated interpersonal trauma and comorbid PTSD, who received NET in a community mental health care context. The inclusion criteria were: outpatients with (a) the existence of SMI, defined as the presence of a bipolar, major depressive, schizophrenia-spectrum, or personality disorder according to the Mini-International Neuropsychiatric Interview (MINI)-plus) [20, 21] and/or the Structured Clinical Interview for DSM-IV Personality Disorders (SCID-II) (First, Spitzer, Gibbon, & Williams, 1995), with reduced global functioning according the Global Assessment of Functioning (GAF)-score < 60 [22, 23] during two or

more years according to chart diagnosis; (b) a trauma history including repeated physical and/or sexual abuse according to the Life of Events Checklist for DSM-5 (LEC-5); [24, 25] and (c) the existence of PTSD according to the Clinical-Administered PTSD Scale for DSM-5 (CAPS-5) [26-28]. The exclusion criteria were: outpatients with (a) provision of other trauma-focused treatment within 12 months prior to the study; (b) antisocial personality disorder; (c) dissociative identity disorder; or (d) the provision of involuntary treatment following the Dutch Mental Health Law.

Recruitment

The study was carried out in 10 local Flexible Assertive Community Treatment (FACT) teams [29] located in five geographic regions of a large Mental Health Centre in the Netherlands. FACT-team professionals (mainly psychiatrists and specialized psychiatric nurses) screened their patients for trauma and PTSD with the Trauma Screening Questionnaire (TSQ) [30]. After positive screening on the TSQ, the PTSD Checklist for the DSM-5 (PCL-5) was used to verify all PTSD symptoms [30-32] and 27 patients with repeated interpersonal trauma and PTSD were selected.

Patients received oral information about NET from their therapists and were asked to participate in the study. The researcher then provided written information and called after 1 week to check whether information was clearly explained and asked for oral consent. Written consent was obtained from all patients before the inclusion interview. Considering the vulnerable position of SMI patients, FACT-team members who knew their patients, were asked to recruit possible eligible patients. They were informed that they could stop with NET and/or participating in the study at any time without reason. Information included also a statement that personal and clinical data were processed anonymously [33]. They were not rewarded for participating. The recruitment lasted from April 2016 up to January 2018.

Intervention

The NET was conducted according to the Dutch NET manual [34, 35] which is based on the manual outlined by Schauer, Neuner & Elbert [13]. NET was offered by five therapists (three Nurse Practitioners and two Clinical Psychologists) in a maximum of 16 weekly sessions [14] from May 2016 up to October 2018. The therapists were recruited from different FACT-teams at the Mental Health Centre and followed a three-day NET training by qualified trainers in 2015-2016 [36]. They completed additional group video supervision in ten 90-minutes sessions by a trained NET-supervisor during the study. FACT was continued during NET, and comprised of the usual coordinated multidisciplinary treatment interventions for outpatients with SMI, including pharmacotherapy alongside collaborative care, which consisted of case management, crisis interventions and outreach nursing care [37, 38]. During NET treatment, minimal biweekly supportive interventions by other FACT-team members was requested as an important condition, because of the vulnerability of patients with SMI. In this period, the patients did not receive any other psychological treatment or benefits.

Outcomes

The primary outcomes were PTSD and dissociative symptoms. Remission of PTSD was based on the number and severity of symptoms according to CAPS-5 rules [26-28]. The secondary outcomes were SMI symptoms, care needs, quality of life, global functioning, and care consumption.

Assessments

At baseline, demographic data were collected via the electronic patient record (EPR) and included gender, age, marital status, cultural background, education, living condition, and employment. Clinical characteristics consisted of the verification of the primary SMI diagnosis, duration of illness, suicide risk, suicide attempts, and substance abuse were collected with the M.I.N.I-plus [20, 21]. During the study, it was decided to monitor long term changes in diagnosis, substance abuse, and suicide risk with a second assessment with the M.I.N.I.-plus at follow up (T2). Therefore, additional ethical approval was obtained from the Committee on Research Involving Human Subjects Arnhem-Nijmegen. The number and duration of interpersonal traumatic event types were collected with the LEC-5 [24, 25]. PTSD subtype and duration were collected according to the CAPS-5 [26, 27].

Data for the primary and secondary outcomes were collected at three moments: at baseline (T0), one month (T1) and seven months (T2) after NET. PTSD symptoms and severity were assessed for with the CAPS-5 [26, 27] and dissociative symptoms with the Dissociative Experiences Scale (DES) [39]. SMI symptoms were assessed with the Health of the Nation Outcome Scale (HoNOS) [40], care needs were assessed with the Camberwell Assessment of Needs (CAN) [41], quality of life was assessed with the Manchester Short Assessment of quality of life (MANSA) [42] and global functioning was assessed with the GAF [23]. These assessments were performed by a trained and independent research assistant, who was supervised by the first author. The HoNOS was assessed by the primary care provider because this instrument is focused on long-term observation. For detailed information on content, validity, and reliability of the mentioned diagnostic instruments, consult the study protocol [14].

Care consumption was defined as the number of therapeutic contacts, including duration in minutes and prescribed medications. These data were collected via the electronic patients record by the first author for the following period: six months before T0 up to and including T2. The prescribed medications comprised four groups of psychiatric medication. For each group, a standard equivalent was calculated for: a) benzodiazepines: diazepam [43], (b) anti-depressants: fluoxetine [44, 45], (c) anti-psychotics: haloperidol [46, 47] and (d) mood stabilizers: topiramate because this medication was most commonly prescribed [48]. The cumulative dose for each group of medication was calculated for each participant in the defined periods.

Sample size and statistical methods

The intended sample size was 25 participants. This size was based on the clinical feasibility of performing the intervention in the mental health centre. It was assumed that each of the five therapists in their geographic region, could provide NET to five participants within two years. A sample size was not calculated because the great degree of uncertainty, but the chosen number is in line with other feasibility trials with a continuous end-point [49, 50].

To describe demographics and clinical characteristics at baseline, means (s.d.) or median (interquartile range) were used for continuous data, depending on whether there was a normal distribution. Percentages were obtained for categorical data.

Because of the hierarchical structure of our study (repeated-measures nested within participants) we performed a linear mixed models for the analysis of the continuous course of illness outcomes. The duration of contacts had a skewed distribution and therefore a log transformation was performed. The log-transformed outcome was also analysed with a linear mixed model. The number of contacts was analysed with a generalized linear mixed model with a negative binomial distribution. For all these

analyses we used a model with a random intercept and all other variables fixed. A P-value of < 0.05 was considered to be statistically significant, based on two sided tests. The analysis was done with IMB SPSS Statistics 25 for Windows. Table 2 presents back-transformed results.

For the use of psychiatric medication, the cumulative dose was calculated for the following periods: 6 months before T0; between T0 and T1; and 6 months thereafter, at T2. Medications were prescribed once a month to once every 3 months. Therefore, doses were expressed in daily per month.

5.3 RESULTS

Participant flow

In total, 27 eligible patients were contacted and all accepted NET treatment. One man (age 59 years) and one women (age 56 years) received NET, but did not consent to participate in the study. The other 25 patients did consent to participate in the study. Of these, two patients (both female, ages 23 and 39 years) withdrew before inclusion because of somatic illness and family circumstances, respectively. The remaining 23 patients started with NET within 1 week after inclusion. Most of them had never received TFT in the past. Two female patients dropped out during NET, but no serious events occurred.

Baseline demographics and clinical characteristics

The mean age of the participants (*n*=23) was 49.9 years (s.d. 9.81) The majority were women (*n*=19). Four participants had a non-western cultural background. Of all the participants 14 had a middle education, two had a high education, and only one was employed. Twelve participants were married or lived together, seven lived alone, and four were living in a sheltered house.

Clinical characteristics show that the participants experienced three to eight years (median) emotional, physical and/or sexual abuse during childhood and/or adulthood. The mean duration of PTSD was 24.1 years (s.d. 14.48).

Major Depressive Disorder was overrepresented among the participants (*n*=15), in contrast to Schizophrenia Spectrum Disorder (*n*=4) and Bipolar Disorder (*n*=4). Personality Disorder did not appear in this group. The mean duration of SMI was 26.2 (SD 12.2). Thirteen participants attempted suicide in the past and ten participants had current high suicide risk. Substance abuse was relatively low. See Table 1 for further details.

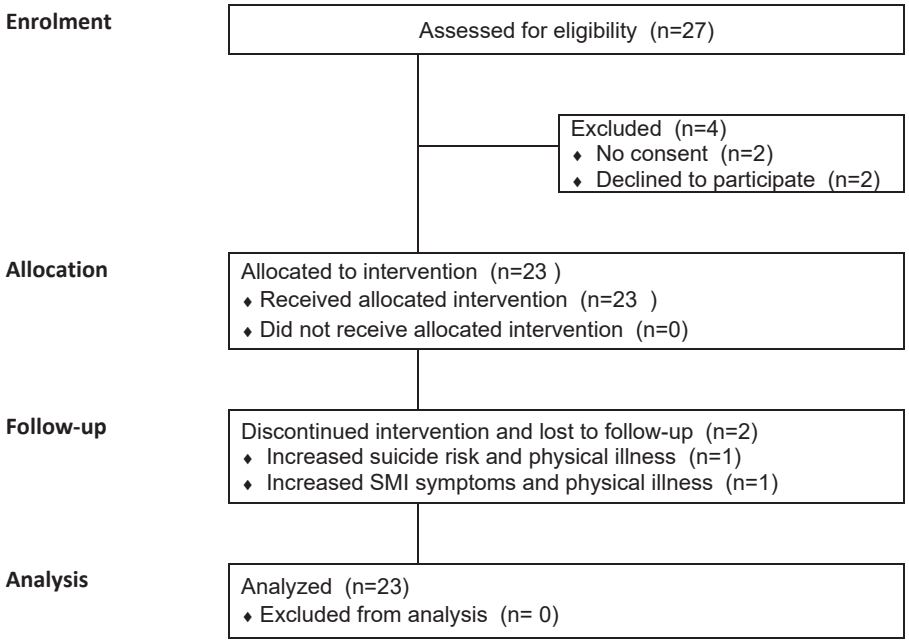

Figure 1. Consort flow diagram

Provision of NET

Of the 23 participants who started with NET, two of them discontinued treatment prematurely after one session and four sessions, respectively. The other 21 participants received 8–15 (median 11, interquartile range 2.5) weekly NET sessions. Duration of NET was 10–43 weeks (median 15), including four cases with interrupted treatment because of somatic problems (one participant), family circumstances (one participant), experienced stress from the therapy (one participant) and change of therapist (one participant), but eventually all finished NET after these breaks.

Analysis with mixed models included 23 participants, based on the intention-to-treat principle and taking missing values into account. Twenty-one participants completed the intervention and the study. There was no measurement of one participant at T1, and another at T2. Also missed were two HoNOS measurements at T2. These participants were in remission for PTSD and major depressive disorder and left the mental health centre after treatment; therefore, they could not be observed by the primary care provider. All other measures were completed by the research assistant.

PTSD and dissociative symptoms

The number of PTSD symptoms and PTSD severity (CAPS-5) decreased over time between baseline, post-treatment and follow-up. The number and severity of each PTSD cluster symptoms decreased over time between baseline and follow-up. Intrusion, avoidance, cognition and mood symptoms decreased during and after treatment, whereas arousal and reactivity were decreased at follow-up (see Table 2). Severity of dissociative symptoms (DES) also decreased between baseline, post-treatment and follow-up.

Eight participants were in remission for PTSD at post-treatment and three other participants were in remission at follow-up. Remission rates in the diagnostic subgroups were almost similar: 8 out of 15 for depressive disorder, 2 out of 4 for bipolar disorder and 1 out of 4 for schizophrenia spectrum disorder.

SMI symptoms, care needs, quality of life and global functioning

Severity of SMI symptoms (HoNOS) decreased between baseline (T0) and follow-up (T2). No significant changes occurred in quality of life (MANSA) and care needs (CAN). Global functioning (GAF) increased over time, between post-treatment and follow-up (see Table 2).

Between T0 and T2, suicide risk shifted from high (44% to 35%) and medium risk (13% to 5%) to low risk (26% to 35%). In the group as a whole, substance misuse decreased from 30% to 24%. One participant had alcohol and substance use at baseline, but was abstinent for both at follow-up. Of the 11 participants in remission for PTSD, five were also in remission for major depression at follow-up (MINI-plus).

Care consumption

The number of contacts changed from 35 in the 6 months before treatment (T0), to 40 during treatment (T0 to T1), and to 31 during the 6 months after treatment (T1 to T2), although this was not statistically significant (overall P = 0.572). However, the geometric mean of the duration of the contacts increased 1.85 times (95%CI 1.35–2.55) from 2021 min (34 h) in the 6 months before treatment (T0) to 3749 min (62 h) for the treatment period T1–T0, whereas it decreased by a factor 0.63 (95%CI 0.48–0.86) to 1271 min (21 h) in the 6 months after treatment (T2) compared with the 6 months before treatment (T0; overall P = <0.001). Before and during the study, 21 participants received psychiatric medication. Prescribed doses of antipsychotics (n = 13) and benzodiazepines (n = 16) were the most reduced. Mood stabilisers (n=5) also decreased, but the number of consumers was small. Antidepressant (n = 15) doses increased during NET and did not decrease between post-treatment and follow-up. The trends in medication are shown in Figure 2.

Harms

No serious events occurred during NET and follow up. In addition, none of the participants needed hospitalization or crisis management during the study [14].

Table 1. Demographic and clinical characteristics at baseline (n=23).

		N	%
Demographics			
Age, years	Median and mean (SD)	49.9	(9.81)
Gender	Female	19	82.6
	Male	4	17.4
Cultural background	Dutch	18	78.3
	Western Non-Dutch	1	4.3
	Non-Western	4	17.4
Education	Low	7	30.4
	Middle	14	60.9
	High	2	8.7
Employment	Employed	1	4.3
	Sheltered employed	8	34.8
	Unemployed	14	60.9
Living condition	Married/cohabiting	12	52.2
	Alone	7	30.4
	Sheltered housing	4	17.4
Clinical characteristics			
SMI diagnosis (MINI-plus)[1]	Schizophrenia Spectrum Disorder	4	17.4
	Bipolar Disorder	4	17.4
	Major Depressive Disorder	15	65.2
	Duration SMI, years, mean (SD)	26.2	(12.2)
Current suicide risk (MINI-plus)	No	4	17.4
	Low	6	26.1
	Medium	3	13.0
	High	10	43.5
	Suicide attempt ever	13	56.5
Current substance abuse (MINI-plus)	No	15	65.2
	Drugs	7	30.4
	Alcohol and drugs	1	4.3
Abuse (duration) (LEC-5)[2]	Type of abuse (no. of subjects)	Median	IQR
Childhood (duration <16 years)	Emotional (n=16)	8.0	5.5
	Physical (n=16)	5.5	8.0
	Sexual (n=12)	3.0	6.0
Adulthood (duration ≥ 16 years)	Emotional (n=11)	6.0	22.0
	Physical (n=13)	3.0	8.5
	Sexual (n=8)	4.5	8.0
		Mean	SD
Reported traumatic events	Total number	8.0	1.52
Post-traumatic Stress Disorder (PTSD) (CAPS-5)[3]	Total number of symptoms	14.0	2.44
	Total severity	40.0	7.70
	Duration, years	24.1	14.5
	Dissociative subtype, No., (%)	5	(21.7)

[1] MINI Plus, Mini-International Neuropsychiatric Interview; [2] LEC-5, Life Events Checklist for DSM-5; [3] Clinician-Administered PTSD Scale for DSM-5.

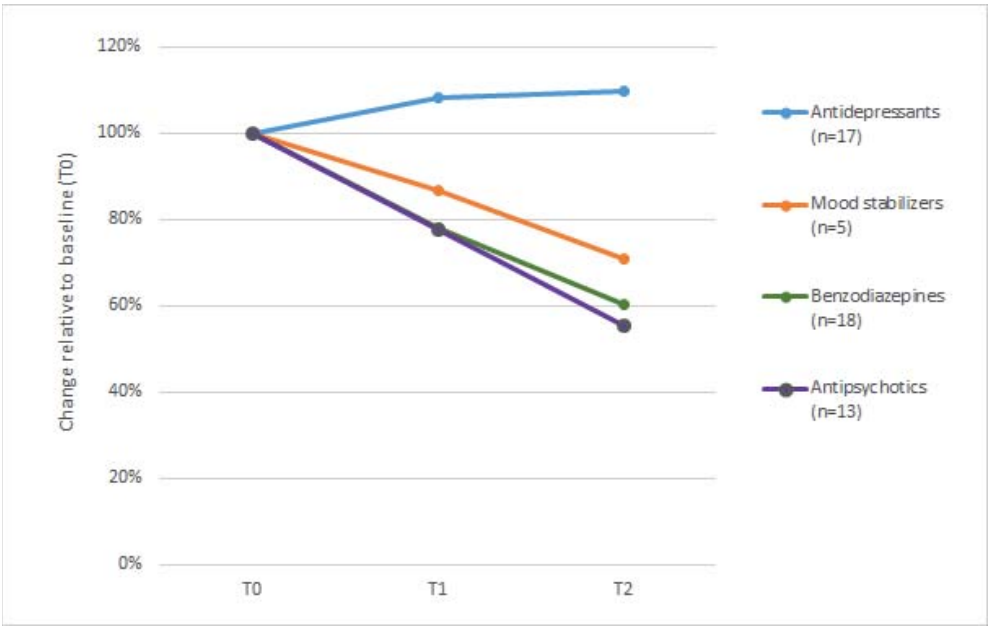

Figure 2. Average medication dose before baseline (6 months before T0), during treatment (T0 to T1) and after treatment (T1 to T2); dose relative to medication before baseline.

5.4 DISCUSSION

Main findings

To our best knowledge, this is the first study which examined the feasibility and applicability of NET for comorbid PTSD in SMI outpatients. PTSD symptoms and severity thereof, reduced significantly at posttreatment and follow up. All four PTSD clusters showed significant reduction of symptoms, whereas intrusions, arousal and reactivity decreased more slowly than symptoms of avoidance, cognitions and mood. These results are in line with other controlled NET studies in vulnerable patients such as children and adolescents [51], patients with borderline personality [17], elderly [52], refugees [15], or asylum seeking refugees with PTSD and depressive disorder [53]. Of the 23 participants, 11 (48%) were in remission for PTSD at follow up. This corresponds to other NET studies that reported 38%, 55%, and 71% [54, 55].

Table 2. Results of primary and secondary outcomes based on a mixed model analysis for repeated measures of the full analysis set.

	Baseline (T0)	*1 month after NET (T1)*			*7 months after NET (T2)*			*Overall*
Outcome	Mean (95%CI)	Mean (95%CI)	LSMD (95%CI)	*P-value*	Mean (95% CI),	LSMD (95%CI)	*P-value*	*P-value*
Primary outcomes for PTSS								
CAPS-5, total symptoms (0-20)	13.65 (11.83;15.47)	11.15 (9.25;13.04)	-2.50 (-4.19;-0.82)	0.005	8.82 (6.93;10.71)	-4.83 (-6.52;-3.14	<0.001	<0.001
CAPS-5, total severity (0-80)	37.91 (32.93;42.90)	31.90 (26.76;37.04)	-6.01 (-10.02;-2.01)	0.004	24.54 (19.40;29.68)	-13.37 (-17.38;-9.37)	<0.001	<0.001
CAPS-5, total severity clusters								
B Intrusions (0-20)	10.78 (8.95;12.61)	9.01 (7.12;10.90)	-1.77 (-3.33;-0.22)	0.026	6.56 (4.66;8.45)	-4.23 (-5.78;-2.67)	<0.001	<0.001
C Avoidance (0 - 8)	4.00 (3.35;4.65)	2.51 (1.82;3.21)	-1.49 (-2.38;-0.59)	0.002	1.87 (1.17;2.56)	-2.13 (-3.03;-1.24)	<0.001	<0.001
D Cognitions and mood (0-28)	13.70 (11.66;15.73)	11.16 (9.04;13.29)	-2.53 (-4.52;-0.55)	0.014	9.69 (7.57;15.73)	-4.00 (-5.99;-2.02)	<0.001	<0.001
E Arousal and reactivity (0-24)	9.43 (7.79;11.08)	9.01 (7.38;10.82)	-0.34 (-1.90;1.23)	0.664	6.38 (4.67;8.10)	-3.05 (-4.61;-1.49)	<0.001	<0.001
DES, total severity (0-100)	27.79 (21.17;34.42)	22.41 (15.65;29.18)	-5.38 (-9.77;-0.99)	0.018	20.97 (14.20;27.73)	-6.83 (-11.21;-2.44)	0.003	0.008
Secondary outcomes for SMI								
HoNOS, total severity (0-48)	12.30 (9.79;14.81)	10.04 (7.34;12.73)	-2.27 (-4.70;0.16)	0.067	9.937 (7.31;12.54)	-2.38 (-4.72;-0.03)	0.047	0.083
CAN, total severity (0-44)	10.22 (8.21;12.22)	10.79 (8.72;12.85)	0.57 (-1.05;2.19)	0.482	9.91 (7.84;11.98)	-0.30 (-1.92;1.31)	0.705	0.562
MANSA, total quality (12-84)	52.39 (47.77;57.01)	55.38 (50.67;60.09)	2.99 (0.28;5.95)	0.048	53.04 (48.33;57.75)	0.65 (-2.31;3.61)	0.660.	0.117
GAF, total functioning (0-100)	49.39 (47.00;51.78)	49.24 (46.72;51.77)	-0.15 (-2.93;2.64)	0.915	53.39 (50.86;55.91)	4.00 (1.21;6.78)	0.006	0.008
Care consumption [1]								
Contacts per period (number)	35.0 (22.8–53.8)	40.0 (26.0–61.4)	5.0 (−10.8 to 31.1)	0.598	30.6 (19.9–47.0)	−4.4 (−14.6 to 15.7)	0.597	0.572
Duration of contacts (minutes)	2021 (1475–2770)	3749 (3111–4518)	1728 (1163–2388)	<0.001	1271 (803–2010)	−750 (−940 to −526)	0.006	<0.001

NET, Narrative Exposure Therapy; LSMD, least squares mean difference; CAPS-5, Clinician Administered PTSD Scale for DSM-5; DES, Dissociative Experiences Scale; SMI, severe mental illness; HoNOS, Health of the Nation Outcome Scale; CAN, Camberwell Assessment of Needs; MANSA, Manchester Short Assessment of Quality of Life; GAF, Global Assessment of Functioning scale.

[1] Results for the number and duration of contacts (obtained from the electronic record) are based on analyses on a logarithmic scale; table presents back-transformed results. The columns T0, T1 and T2 refer to the period before, during and after treatment by NET.

Our results suggests that SMI patients may benefit from NET just like other patient groups. So far, NET has not studied specifically in SMI patients. Until now, most NET studies excluded patients with psychosis, bipolar disorder, substance abuse, and suicidal ideations [17, 51-53]. One case study reported positive results of NET in a refugee with PTSD and psychotic features [56]. Mørkved et al [54] compared NET and prolonged exposure therapy (PE) for PTSD and argued that NET and PE have several commonalities when it comes to the principals of exposure. An important feature of NET is that trauma-processing is never an isolated event, but is always embedded in the context of a traumatic event and in the life history as a whole. Given this focus on the autobiographical elaboration of traumatic experiences, NET is particularly suited for populations with multiple trauma and complex mental health conditions [16].

Comparing NET with PE makes sense to the extent that it has shown to be effective in SMI patients with psychotic disorders including schizophrenia, bipolar, and depressive disorders in a controlled study. Dissociation, substance use and suicidality risk were not excluded in this study. Results showed that there was no increase of hallucinations, dissociation, or suicidality [9, 12]. The findings in our study are in line with these results: dissociation, suicidality risk, and substance mis abuse were also not excluded, and all showed reduction during and after NET. Severity of dissociative symptoms also declined significantly at posttreatment and follow up. These findings are in line with some other NET studies and other TFT studies [17, 55, 57]. Also, a meta-analysis on the impact of dissociation suggests that pre-treatment dissociation does not determine trauma-focused psycho-therapy outcomes in PTSD [57].

SMI symptoms were assessed with generic measures to allow for comparisons across diagnostic groups [58]. The coherence of the SMI outcomes was low: a slight improvement in SMI was seen based on HoNOS, there were no significant changes in perceived care needs (CAN) and quality of life (MANSA) based on self-reporting, and care providers concluded that global functioning (GAF) was significantly increased. The MINI-plus is a diagnostic and more specific instrument to measure mental disorders, which, in this study, showed remission in 5 out of the 15 participants with major depression, and over all lower disease burden, suicide risk, and less substance use. This is partly comparable with the results of a systematic review of outcomes for psychological interventions for PTSD in psychosis. For prolonged exposure and EMDR, secondary outcomes for psychopathology and distress showed significant reduction, especially for depression and anxiety, but social functioning did not improve. The long duration of SMI and additional social isolation are supposed to be influencing factors [59].

The duration of contacts increased during NET (T0 toT1), but decreased significantly during the six months follow up (T1 to T2), which might reflect less burden of disease. Doses of prescribed benzodiazepines, anti-psychotics and mood stabilisers also decreased during and after NET. This suggests that patients experienced less anxiety, irritability, arousal, reactivity and showed reduction of psychotic and bipolar symptoms. In contrast, doses of antidepressants slightly increased during NET and did not change at follow up. Antidepressants were indicated for both depression and PTSD, and are more difficult to phase out, especially the selective serotonin reuptake inhibitors [60]. To our knowledge, this is the first study on psychological interventions for PTSD in SMI, that takes into account care consumption, expressed as contacts and prescribed medication [59, 61].

Findings in context: treating PTSD in SMI outpatients

Our results support the notion that SMI outpatients with comorbid PTSD, can tolerate intensive trauma-focused therapy like NET. The long-standing clinical perception of vulnerability of SMI patients, has not only resulted in appropriate psychiatric care but unfortunately also to underestimate resilience of SMI patients. This perception may influence under-diagnosis, overlooking trauma histories and not recognizing comorbid PTSD, all contributing to under-treatment [1, 2, 7, 62]. Patients and care providers have to balance resilience and vulnerability in careful conversations, to consider the right time and circumstances for treatment. This study was therefore embedded in clinical practice where optimal care and support by FACT-team members was an important condition. Given that the overall disease burden was high and TFT is often perceived as intensive, most of the participants could endure and tolerate NET. As no serious adverse events occurred, no crisis management was required and no patients were admitted to hospital, this underlines the applicability and safety of NET in this population.

Strengths and limitations

A strength of this study is that it was conducted in the real life clinical context. NET was provided to SMI outpatients in a familiar environment with support from their known care providers from the certified FACT-teams. Diagnostic assessments (i.e. PTSD and SMI) were in line with clinical practice and in addition, routine outcome measurements for SMI were used. So NET fits also well in the workflow of the involved professional, which is helpful for future implementation. Furthermore, this strategy avoids extra diagnostic burden and ensured the applicability and implementation in clinical practice.
The second strength was that the five trained and certified NET therapists were all FACT-team members and experienced with SMI outpatients. They followed the NET protocol and received group supervision from a trained NET-supervisor [36]. In this way, they also were able to discuss questions and dilemmas among NET for SMI outpatients. The use of EPR to monitor prescribed medication and contacts is a third strength, because these objective data were not influenced by oral assessments.

Despite these strengths, the limitations of this study are that it was conducted in a small study population without a control group. Moreover, most participants were female, therefore caution is warranted for statements about effectiveness for men. Also this should be a subject for future research. Therefore, results must be cautiously interpreted. However, the observed changes are in line with proven effect of PE, which shares important principles with NET. Second, generalisability is limited, as no subgroup analysis could be done by age, gender, or primary diagnosis. However, PE and EMDR have be shown to be effective in psychosis [59] and SMI [61], where NET is effective in major depressive disorder [53]. Thirdly, the used routine outcome measurements are possibly not responsive and distinctive enough with regard to SMI symptoms, care needs, and quality of life [63]. Finally, implementing this intervention in daily clinical practice, also meant that the NET protocol and the agreed FACT-support, were not always strictly followed. This concerns mostly interruptions of NET and replacement from care providers.

Interpretation and recommendations

In conclusion, our results support that NET is feasible and applicable to SMI outpatients in a FACT-context. NET seems a valuable addition to other evidence based trauma focused therapies (i.e. PE, EMDR, and CBT) and is specifically indicated for PTSD related to repeated interpersonal trauma. Given the high prevalence of repeated interpersonal trauma and PTSD in SMI patients [2, 3] and the burden of disease, offering TFT to these patients is important. Relevant screening by means of structured diagnostic interviews for trauma history, PTSD, and primary SMI disorder are recommended in this group. Using more specific diagnostic instruments to evaluate changes in SMI, could help to implement appropriate care. These strategies require sufficient training for therapists and supporting FACT-team members. In this context, it is helpful and encouraging that National Health Institutes are increasingly convinced of the importance to develop trauma informed care policies in mental health systems [7].

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Ring the bells that still can ring

Forget your perfect offering

There is a crack, a crack in everything

That's how the light gets in…

Leonard Cohen, Anthem 1992, London 2016

Chapter 6

Investigating the Efficacy and Experiences With Narrative Exposure Therapy in Severe Mentally Ill Patients With Comorbid Post-traumatic Stress disorder Receiving Flexible Assertive Community Treatment: A Mixed Methods Study

Maria Mauritz

Peter Goossens

Ruud Jongedijk

Hester Vermeulen

Betsie van Gaal

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ABSTRACT

Background: Severe mentally ill patients with repeated interpersonal trauma and post-traumatic stress disorder (PTSD) have a negative illness progression. Traumas are often not treated because of their vulnerability. Narrative Exposure Therapy (NET) is an effective trauma therapy. It is unknown whether NET is effective and tolerable in these patients receiving community mental health care.

Objectives: The objectives of this paper are 1) to gain insight into patient's experiences before, during and after NET concerning changes in PTSD, dissociative and severe mental ill symptoms, care needs, quality of life, and global functioning**;** 2) to identify factors that influence diagnostic changes after NET as compared to patient's experiences. These insights will help to decide whether NET should be incorporated in usual care for these patients**.**

Design: A mixed methods convergent design consists of a grounded theory approach with thematic analysis followed by a merged analysis, comparing quantitative, and qualitative data for each participant and by means of a joint matrix. Participants: Adult psychiatric outpatients (age, 21–65) with post-traumatic stress disorder (PTSD) related to repeated interpersonal trauma were indicted for the study.

Methods: Baseline demographics and clinical characteristics were assessed. Qualitative data were collected 3 months after NET using individual semi-structured in-depth interviews. The merged analysis compared quantitative and qualitative results for each participant.

Results : Twenty three outpatients (female, 82%) with a mean age of 49.9 years (SD 9.8) participated in the study. Participants experienced NET as intensive, and most of them tolerated it well. Afterwards, eighteen participants perceived less symptoms. Mixed analysis showed substantial congruency between quantitative scores and participants' perceptions of PTSD, dissociative symptoms, and CAN (Cohen's kappa > 0.4). Remission of PTSD was associated with sufficient experienced support.

Conclusion: Outpatients with severe mental illness underwent intensive NET, and most of them tolerate it well. This therapy is clearly efficacious in this group.

6.1 INTRODUCTION

The attention given for the high prevalence rates of physical abuse (47–65%), sexual abuse (36–37%), end post-traumatic stress disorder (PTSD) (30–34%) in patients with severe mental illness (SMI) is still growing [1-3]. The need for adequate diagnostics and treatment is increasingly recognized because trauma and PTSD have a negative influence on the course of SMI, including an increased risk of poor physical health; addiction; problems with social, occupational, and community functioning; reduced quality of life; and criminalization [1, 4-6]. Post-traumatic stress disorder has been also associated with substantial medical and economic burden. Recent public health preventive innovations have included integrated medical and behavioral healthcare, such as modifications of trauma focused treatment (TFT), the use of novel and augmentative psychopharmacological agents, and the use of technology. Research on the impact of traumatic stress, as well as prevention strategies for PTSD, has resulted in an improved understanding of its impact and more effective public health interventions [7].

Trauma-focused cognitive behavior therapy is the best validated treatment for PTSD, but it has stagnated over recent decades, and only two-thirds of patients with PTSD adequately respond to this intervention. Globally, most people with PTSD do not access evidence-based treatment, and this situation is much worse in low- and middle-income countries. Bryant [8] advocates better management so that more patients can benefit from TFT [8]. Studies have shown that TFT, such as prolonged exposure, cognitive behavioral treatment, and, eye movement desensitization reprocessing (EMDR), have proved to be effective for patients with major depressive, bipolar, and psychotic disorders with comorbid PTSD [3, 9-12].

Narrative exposure therapy (NET) is a relatively new TFT [13]. NET is suited for people who are exposed to repeated traumatic events during the course of their life. NET has a lifetime perspective, integrating an exposure-based narration of traumatic experiences together with an elaboration of these experiences in the autobiographical context. NET appeared effective in vulnerable, traumatized groups, like refugees, child soldiers, patients with early childhood trauma, and other vulnerable, traumatized groups, among which are patients with tendency for dissociation, major depressive disorder, or borderline personality disorder, and is also suitable for children and older adults [14-16]. Until now, NET has not been specifically investigated in outpatients with SMI, and, to our knowledge, there are no qualitative and mixed studies on NET [15, 17].

In a mixed methods study consisting of a quantitative and qualitative strand, NET was offered to outpatients with SMI with comorbid post-traumatic stress disorder associated with repeated interpersonal trauma, and they received flexible assertive community treatment (FACT). This Dutch variant of community mental healthcare consists of coordinated multidisciplinary treatment interventions for outpatients with SMI, including collaborative care, pharmacotherapy, case management, crisis interventions, and outreaching nursing care [18]. In another article, we described quantitative results, showing that diagnostic PTSD scores decreased from a mean of 37.9 before NET (T0) to 31.9 after post-treatment (T1) (–6.0, 95% CI –10.0 to –2.0) and to 24.5 at follow-up (T2) (–13.4, 95% CI –17.4 to –9.4). Dissociation, psychiatric symptoms, contacts, and medication decreased, global functioning increased, and quality of life and perceived needs did not significantly change [19]. The purpose of the present study is to evaluate outpatients with NET in SMI by a qualitative analysis of

patient perceptions and to compare this to the quantitative assessment reported before. We are working on another study that analyzes the interviews by full grounded theory on the meaning of NET.

6.2 OBJECTIVE

The objectives of this study are (1) to gain insights into patients' experiences before, during, and after NET concerning changes in post-traumatic stress disorder, dissociative and severe mental ill symptoms, care needs, quality of life, and global functioning and **(**2) to identify factors that influence the results of NET in terms of diagnostic changes compared with patients' experiences. These insights will help in balanced decision-making on whether NET should be incorporated in usual care for these patients [20].

6.3 MATERIALS AND METHODS

Design

The intervention was evaluated by means of a convergent mixed methods design, including a quantitative and a qualitative strand [21-23]. The quantitative strand had a single-group pre-test-post-test repeated-measures design and was published elsewhere [19]. The qualitative strand was based on a grounded theory approach and consisted of individual semi-structured in-depth interviews with all participating patients. The present integration of these strands focuses on interpreting how qualitative results enhance the understanding of quantitative outcomes in a one-to-one analysis.

This study was registered in The Netherlands National Trial Register, Trial NL5608 (NTR5714) registration date: 2016-02-18; first recruitment: 2016-03-15. The Committee on Research Involving Human Subjects, Arnhem-Nijmegen, provided ethical approval (No. 1843–2015). The study was carried out in a mental health center in the Netherlands from April 2016 to January 2019.

Participants: outpatients with severe mental illness with comorbid post-traumatic stress disorder

The target population consisted of adult outpatients with SMI (age, 21–65) who received FACT in a community mental healthcare context. Due to the high prevalence of trauma exposure and post-traumatic stress disorder (PTSD), outpatients with SMI were screened for traumatic events and the presence of post-traumatic stress disorder. Patients with comorbid post-traumatic stress disorder and a history of repeated interpersonal trauma were eligible for NET.

The inclusion criteria were outpatients with (1) SMI, defined as the presence of a bipolar, major depressive, schizophrenia spectrum disorders according to the Mini-International Neuropsychiatric Interview (M.I.N.I.-plus) or the presence of a personality disorder according to the Structured Clinical Interview for DSM-IV Personality Disorders (SCID-II), with reduced global functioning according to the Global Assessment of Functioning (GAF)-score < 60 during 2 or more years according to chart diagnosis; (2) a trauma history including repeated physical and/or sexual abuse according to the Life of Events Checklist for DSM-5 (LEC-5); and (3) the existence of post-traumatic stress disorder according to the Clinical-Administered Post-traumatic Stress Disorder Scale for DSM-5 (CAPS-5). The exclusion criteria were outpatients with (1) the provision of other TFT within 12 months prior to the study; (2) antisocial

personality disorder; (3) dissociative identity disorder; and (4) the provision of involuntary treatment following the Dutch Mental Health Law.

Inclusion

NET was first indicated by multidisciplinary consultation in the flexible assertive community treatment team. Patients received oral and written information about NET from the therapist. When the patients decided to accept NET, the therapist asked them to participate in the study. Written information about the entire study was provided by the researcher (the first author). After 1 week, the patients were called by the researcher to verify whether the information was well understood. If so, patients were asked to provide oral and written consent. The participants received the following information about the researcher: a female nurse practitioner and scientist working at the mental health center but who was not involved in patients' flexible assertive community treatment. The researcher had no relationship with the participants prior to the commencement of the study, except for one female patient who had received flexible assertive community treatment from the researcher 4 years earlier.

Intervention

NET was conducted according to the Dutch manual [24, 25], which is based on Schauer et al. [26], and consisted of weekly 90-min sessions with a minimum of five and a maximum of sixteen sessions. During NET, flexible assertive community treatment was continued with minimal biweekly supportive interventions by the community treatment team members, mainly nurses. This was asked as an important condition because of the vulnerability of outpatients with SMI. NET was provided by five therapists, consisting of three nurse practitioners and two clinical psychologists who were recruited from different flexible assertive community treatment teams at the Mental Health Center and were certified as NET-therapists after following a 3-day NET training by qualified trainers in 2015–2016. They completed additional group video supervision in ten 90-min sessions by a trained NET-supervisor during the study [27].

Research team and reflexivity

The age of the team members was given at the start of the analysis in January 2019. The first author, female and aged 53, is a nurse scientist (MSc) and a nurse practitioner (APRN) in mental healthcare. She performs psychiatric and nursing diagnostics and care, pharmacotherapy, psychological treatment, and mainly works with outpatients with traumatized severe mental condition. She is a certified NET-therapist and experienced in other TFT such as eye movement desensitization reprocessing and prolonged exposure [28]. Her academic training included qualitative research skills, and she graduated on a grounded theory study of loss and grief in schizophrenia [19, 29]). The second author, male and aged 54, is a nurse scientist (Ph.D.) and nurse practitioner (APRN) in mental healthcare. He is a specialist in bipolar disorders and other severe mental disorders. He is also a part-time professor in Health Sciences and experienced in qualitative, quantitative, and mixed models approaches. The third author, male and aged 59, is a psychiatrist (MD). He introduced NET in the Netherlands and is a certified NET therapist, teacher, and supervisor [24]. The fourth author, female and aged 50, is a clinical epidemiologist (Ph.D.), a full professor in Nursing Science and has extensive experience in quantitated and qualitative research. She supervised the whole study. The fifth author, female and aged 54, is a nurse scientist (Ph.D.) and registered nurse (RN) in an academic hospital care. She is also a senior lecturer and senior researcher in applied nursing sciences and has experience in quantitative, qualitative, and mixed methods approaches.

Data collection

In this convergent design, quantitative and qualitative data were concurrently collected before merging the data [22].

Demographics and clinical characteristics

Demographic data were collected in a former study via the electronic patient record at the baseline and included gender, age, marital status, cultural background, education, living condition, and employment. Clinical characteristics were collected with the M.I.N.I-plus and comprised the primary SMI diagnosis, duration of illness, number of suicide attempts, suicide risks, and substance abuse [19].

Quantitative measurements

Quantitative measurements used in this study were assessed as described before [19, 20]. In short, six quantitative measures of outcomes were used: post-traumatic stress disorder (CAPS) [30], dissociative symptoms (DES)[31], severe mental ill symptoms (HoNOS) [32], CAN [33], quality of life (MANSA) [34], and global functioning (GAF) [35]. These outcomes measured were pre-treatment T0), 1 month (T1) after treatment, and 7 months (T2) after treatment. Care consumption (prescribed medication, number of therapeutic contacts, and duration in minutes) was collected via the electronic patient record from 6 months prior to T0 until 7 months after T2 [19].

Semi-structured in-depth interviews

Semi-structured in-depth interviews were held 3 months posttreatment (T1) and lasted at most 60 minutes. The participants were allowed to choose to have the interview at their home or in the local Mental Health Unit center. Supervised by the second author (PG), the first author (MM) developed a topic list and an interview guide for the semi-structured interviews. Based on the pre-arranged sensitive concepts in the study protocol, perceived changes in post-traumatic stress disorder, dissociative and severe mental Ill symptoms, care needs, and quality of life over time, a topic list, and an interview guide were developed for the semi-structured interviews by MM and supervised by PG. The interview guide was adjusted two times when new relevant topics emerged in the interviews; *Box 1* provides the final topic list and *Supplementary Material 1* provides the final interview guide. MM conducted the interviews and was blinded to the quantitative measurement results to avoid bias based on foreknowledge. Each interview was held with a neutral attitude. All interviews were audiotaped and transcribed verbatim. PG provided written feedback on each transcript after listening to the recordings. Then, MM and PG reflected on the interview style, and they explored new themes and evaluated the interview guide. To provide member checks, the transcripts were summarized by MM and sent to the participants. After 1 week, MM contacted the participants by telephone to verify whether the summary was complete and accurate.

6.4 ANALYSIS

Qualitative data were analyzed independent of the earlier quantitative analysis (objective 1). Subsequently, the mixed methods analysis combined the quantitative measurements with the qualitative results (objective 2) to assess (in)congruency between quantitative measurements and qualitative interview data.

Box 1. Topic list

Topics derived from and arranged by each sensitizing concept

*Experienced severity of symptoms **before, during and after** NET*

- PTSD
- Symptoms of psychotic, bipolar, or depressive disorder
- Suicidality

Changes in care needs

- perceived decreased care needs
- perceived persisting or increased care needs

Changes in quality of life and daily life functioning

- perceived quality of life
- perceived effects on daily life functioning

Influencing factors

- success
- failure

Mauritz, et al. [19]

Qualitative analysis

At the start, the analysis was based on the grounded theory approach to gain more insights into the experiences of the participants. To facilitate the analysis of interview data, the Qualitative Analysis Guide of Leuven was used [36]. This guide is specifically used for interview data and distinguishes two parts with each five stages: First, the preparation of the coding process with paper and pencil work and, second the actual coding process using qualitative software in ten stages of analysis (see *Box 2*).

MM and PG performed all the ten stages, which were carefully documented for *transparency and reproducibility*. After rereading the interviews (1), narrative reports were independently made, compared, discussed, corrected, and integrated (2). A conceptual interview scheme was then derived (3), and a fitting test of the conceptual interview scheme was performed for all interviews by HV, BvG, and RJ. To critically evaluate supporting and contradictory information, *triangulation* included feedback by in-depth discussion with all the authors. Then, corrections and additions were made (4). After *constant comparison* (5), a preliminary list of concepts was drafted (6). Subsequently, Atlas ti 8 was used to link all relevant fragments to appropriate codes (7). Then, a *thematic analysis* was undertaken with a deductive approach for the following concepts: experienced post-traumatic stress disorder, dissociative and severe mental Ill symptoms, care needs, quality of life, and global functioning. This analysis was aimed at meaning, dimensions, and characteristics (8). Extraction of the of the essential structure was displayed using an Excel 2013 file (9) (see *Supplementary Material 2*), and the essential results were described (10).

Box 2. The ten stages of the Qualitative Analysis Guide of Leuven QUAGOL

1. Thorough (re)reading of the interviews to receive a holistic understanding of the respondent's experience
2. Narrative interview report: a brief abstract of the key storylines of the interview
3. From narrative interview report to conceptual interview scheme
4. Fitting-test of the conceptual interview scheme: testing the appropriateness of schematic card in dialogue
5. Constant comparison process: forward-backwards movement between within-case and across-case analysis
6. Drawing up u list of concepts: a common list of concepts as preliminary codes
7. Coding process – back to the 'ground': linking all relevant fragments to the appropriate codes
8. Analysis of concepts: description of concepts, their meaning, dimensions & characteristics
9. Extraction of the essential structure: conceptual framework or story-line
10. Description of the results and description of the essential findings

Adapted from Dierckx de Casterlé, Gastmans et al. 2012, p. 364

Merged data analysis of quantitative and qualitative data

The merged analysis compared the results from the quantitative and qualitative data for each participant by means of a joint matrix, a display that places quantitative results side by side with qualitative themes using Excel 2013 (see *Supplementary Material 2*). The results from the two databases were compared for the following specified dimensions**:** Post-traumatic stress disorder, dissociative symptoms, SMI symptoms, care needs, quality of life, and global functioning. The Excel file listed quantitative results in columns for T0, T1, and T2. For each quantitative outcome, a second column was added to represent qualitative results, while quantitative findings were hidden. Next, both quantitative and qualitative results were compared, and a third column was added to indicate whether quantitative and qualitative results were congruent or incongruent. Subsequently, it was examined how often congruence occurred in participants. This procedure also facilitated triangulation of different methods. The comparisons are presented in supplementary Material 2.

Congruence of structured assessment instruments (CAPS-5, DES, HoNOS, CAN, MANSA, GAF) and patients' perceptions (qualitative interviews) was quantified as the percent agreement and as Cohen's kappa [37], followed by statistical testing using the Fisher exact test [38].

Additional Merged Analysis

During the analysis of the narrative reports (second stage, QUAGOL), MM and PG noticed that professional and informal support was, possibly, an important factor for NET results. At the third stage, the concepts "supportive caregivers" and "significant others" were inserted into the final conceptual scheme as influencing factors. In Step 7 (*Box 2*), we (PG, MM) identified that the patients often mentioned the relevance of support. Subsequently, we decided along with all the authors to investigate a possible relation between perceived care support and whether or not the patients were in remission. The percentage of the patients who were in remission was compared between those who did and those who did not perceive sufficient support, followed by statistical testing (Fisher exact test) [38].

6.5 RESULTS

Participants: outpatients with severe mental illness

As described in Table 1, the study population included 23 adult outpatients with SMI (mean age, 49.9 years; SD, 9.8) with comorbid post-traumatic stress disorder associated with repeated interpersonal trauma, i.e., physical and/or sexual abuse in childhood and/or adulthood. The majority of the 23 participants had a Dutch background (n=18) or were female (n=19). The mean duration of post-traumatic stress disorder was 24.1 years (SD 14.5) [19]. All the participants received NET in a FACT context (n=23) of whom 21 completed NET. Two female participants (age, 50 and 63) terminated NET prematurely because they could not tolerate the exposure to traumatic memories. One of them still agreed to participate in the interview. Therefore, a total of 22 interviews were conducted. Results of the quantitative analysis are provided in Table 2.

Qualitative findings

Post-traumatic stress disorder symptoms

Before NET, the participants experienced many PTSD symptoms, such as anxiety, intrusive thoughts, bad memories, nightmares, avoidance, insomnia, anger, crying, grief, guilt, negative thoughts, worrying, palpitations, pain, and fatigue. Participants who were in remission (n=11) reported that they experienced these symptoms for years and often lived a long time with it. Many of these participants experienced an increase in these symptoms during NET and reported that they were more aware of them:

> During therapy: *"Experiencing grief was terrifying, allowing feelings to surface is tough and I got lost in memories. Nightmares and insomnia increased. Gradually, the nightmares subsided and things got better; I was better able to think about things." Female, aged 48.*

> Before and during therapy: *"I had panic attacks, nightmares, crying fits; I was miserable and didn't go outside." After therapy: "I must say, things are now slowly getting better." Female, aged 38.*

> After therapy: *"I still have nightmares, but then I get out bed [sic], sit with the cat on my lap, and am able to sleep again. I lie awake less often now." Female, aged 55.*

Dissociative Symptoms

Dissociative symptoms are common in PTSD but differ in severity. Thirteen participants were aware of their dissociative symptoms and told about flashbacks, reliving the memory, amnesia, absent and staring, tingling sensations, "magical thinking," and "chaos in the head." During and after narrative therapy, dissociative symptoms decreased in five participants and sometimes disappeared, leading to more self-knowledge and fewer symptoms, which improved the quality of life.

> During and after therapy: *"Occasionally, therapy was a bit more intense, of course, because I noticed more about my life during the sessions, but I do notice that, now, I am just, [...] yes, much better, so to speak. I have no more flashbacks. I am more relaxed; I can put things more into perspective, and also just look back."* Female, aged 46.

> During therapy: *"You say this in the short time that you are there* (having a therapy session) *and, after that, you get even more awareness; often, more memories too, but also more accurate."* Male, aged 57.

> Before therapy: *"I was coming out of myself, floating around, and was magically thinking."* Afterwards, *"I had more re-experiences."* Female, aged, 45.

Severe mental ill symptoms

Before NET, depressive and anxiety symptoms were mentioned by most of the participants. These symptoms included feeling unwell, gloom, lots of crying, seeing everything negative, concentration problems, suicidal thoughts, insomnia, frightened feelings, and panic attacks. These symptoms led sometimes to eating problems, fatigue, and low physical health. During and after NET, 11 participants perceived less symptoms.

> Before therapy: *"At the start, I was experiencing everything very negative."* After therapy: *"Now, I don't have that many crying fits anymore. I feel happy, cheerful, and relieved. I eat better and I look better; I am not so depressed anymore."* Female, aged 61.

> Before therapy: *"I had delusions and continued hallucinations. I was a loner, I felt tense, and I was defensive. After therapy: My psychotic symptoms decreased. I have more self-confidence now."* Male, aged 56.

Table 1. Demographic and clinical characteristics (n=23) [1]

Demographics			
Age, y	Median, mean, (SD)	49.9	(9.81)
		N	%
Gender	Female	19	82.6
Cultural background	Dutch	18	78.3
	Western Non-Dutch	1	4.3
	Non-Western	4	17.4
Education	Low	7	30.4
	Middle	14	60.9
	High	2	8.7
Employment	Employed	1	4.3
	Sheltered employed	8	34.8
	Unemployed	14	60.9
Living condition	Married/cohabiting	12	52.2
	Alone	7	30.4
	Sheltered housing	4	17.4
Clinical characteristics			
SMI diagnosis (MINI-plus)[2]	Schizophrenia Spectrum Disorder	4	17.4
	Bipolar Disorder	4	17.4
	Major Depressive Disorder	15	65.2
	Duration SMI, y, mean, (SD)	26.2	12.2
Current suicide risk (MINI-plus)	No	4	17.4
	Low	6	26.1
	Medium	3	13.0
	High	10	43.5
	Suicide attempt ever	13	56.5
Current substance abuse (MINI-plus)	No	15	65.2
	Drugs	7	30.4
	Alcohol and drugs	1	4.3
Abuse, No, duration, y (LEC-5)[3]		Median	IQR
Childhood (<16 yr)	Emotional (n=16)	8.0	5.5
	Physical (n=16)	5.5	8.0
	Sexual (n=12)	3.0	6.0
Adulthood (≥ 16 yr)	Emotional (n=11)	6.0	22.0
	Physical (n=13)	3.0	8.5
	Sexual (n=8)	4.5	8.0
		Mean	SD
Type trauma's	Total number	8.0	1.52
	Total number of symptoms	14.0	2.44
PTSD (CAPS-5)[4]	Total severity	40.0	7.70
	Duration, y	24.1	14.5
	Dissociative subtype, No., %	5	21.7

[1] Mauritz, van Gaal et al. 2020; DOI: https://doi.org/10.1192/bjo.2020.124).
[2] Mini-International Neuropsychiatric Interview,
[3] Life Events Checklist for DSM-5,
[4] Clinician-Administered PTSD Scale for DSM-5.

Table 2. Results of primary and secondary outcomes based on a mixed model analysis for repeated measures (MMRM) of the full analysis set (FAS)[1].

	Baseline (T0)	*1 month after NET (T1)*			*7 months after NET (T2)*			*Overall*
Outcome	Mean (95%CI)	Mean (95%CI)	LSMD (95%CI)	*P-value*	Mean (95% CI),	LSMD (95%CI)	*P-value*	*P-value*
Primary outcomes for PTSS								
CAPS-5, total symptoms (0-20)	13.65 (11.83;15.47)	11.15 (9.25;13.04)	-2.50 (-4.19;-0.82)	0.005	8.82 (6.93;10.71)	-4.83 (-6.52;-3.14	<0.001	<0.001
CAPS-5, total severity (0-80)	37.91 (32.93;42.90)	31.90 (26.76;37.04)	-6.01 (-10.02;-2.01)	0.004	24.54 (19.40;29.68)	-13.37 (-17.38;-9.37)	<0.001	<0.001
CAPS-5, total severity clusters								
B Intrusions (0-20)	10.78 (8.95;12.61)	9.01 (7.12;10.90)	-1.77 (-3.33;-0.22)	0.026	6.56 (4.66;8.45)	-4.23 (-5.78;-2.67)	<0.001	<0.001
C Avoidance (0 - 8)	4.00 (3.35;4.65)	2.51 (1.82;3.21)	-1.49 (-2.38;-0.59)	0.002	1.87 (1.17;2.56)	-2.13 (-3.03;-1.24)	<0.001	<0.001
D Cognitions and mood (0-28)	13.70 (11.66;15.73)	11.16 (9.04;13.29)	-2.53 (-4.52;-0.55)	0.014	9.69 (7.57;15.73)	-4.00 (-5.99;-2.02)	<0.001	<0.001
E Arousal and reactivity (0-24)	9.43 (7.79;11.08)	9.01 (7.38;10.82)	-0.34 (-1.90;1.23)	0.664	6.38 (4.67;8.10)	-3.05 (-4.61;-1.49)	<0.001	<0.001
DES, total severity (0-100)	27.79 (21.17;34.42)	22.41 (15.65;29.18)	-5.38 (-9.77;-0.99)	0.018	20.97 (14.20;27.73)	-6.83 (-11.21;-2.44)	0.003	0.008
Secondary outcomes for SMI								
HoNOS, total severity (0-48)	12.30 (9.79;14.81)	10.04 (7.34;12.73)	-2.27 (-4.70;0.16)	0.067	9.937 (7.31;12.54)	-2.38 (-4.72;-0.03)	0.047	0.083
CAN, total severity (0-44)	10.22 (8.21;12.22)	10.79 (8.72;12.85)	0.57 (-1.05;2.19)	0.482	9.91 (7.84;11.98)	-0.30 (-1.92;1.31)	0.705	0.562
MANSA, total quality (12-84)	52.39 (47.77;57.01)	55.38 (50.67;60.09)	2.99 (0.28;5.95)	0.048	53.04 (48.33;57.75)	0.65 (-2.31;3.61)	0.660.	0.117
GAF, total functioning (0-100)	49.39 (47.00;51.78)	49.24 (46.72;51.77)	-0.15 (-2.93;2.64)	0.915	53.39 (50.86;55.91)	4.00 (1.21;6.78)	0.006	0.008
Care consumption [2]								
Contacts per period (number)	35.0 (22.8–53.8)	40.0 (26.0–61.4)	5.0 (−10.8 to 31.1)	0.598	30.6 (19.9–47.0)	−4.4 (−14.6 to 15.7)	0.597	0.572
Duration of contacts (minutes)	2021 (1475–2770)	3749 (3111–4518)	1728 (1163–2388)	<0.001	1271 (803–2010)	−750 (−940 to −526)	0.006	<0.001

LSMD, least squares mean difference; CI, confidence interval; CAPS-5, Clinician Administered PTSD Scale for DSM-5; DES, Dissociative Experiences Scale; HoNOS, Health of the Nation Outcome Scale; CAN, Camberwell Assessment of Needs;MANSA, Manchester Short Assessment of quality of life; GAF, global assessment of functioning scale, Number and duration of contacts from electronic record. [1] (Mauritz, van Gaal et al. 2020; DOI: https://doi.org/10.1192/bjo.2020.124). [2] Results for the number and duration of contacts are based on analyses on a ln-scale; table present backtransformed results. The columns T0,T1 en T2 refer to the period before, during, and after treatment

Five participants experienced no important changes in severe mental ill symptoms during and after NET. They told about persisting symptoms, including depressive symptoms, negative feelings, crying, insomnia, no appetite, and inability to enjoy.

> After therapy: *"Nothing has changed since therapy. I have to be honest – I cannot control myself when it comes to eating and sleeping. And that's because I wake up so often. Sometimes, I wake up at three o'clock. Sometimes, I lie down for half an hour and wake up. Then, I am sweating and trembling all over."* Male, aged 43.

Care Needs

The most expressed need was good care support during NET. The participants mentioned that it was very important to have appropriate care support from trusted flexible assertive community treatment nurses, close relatives, and friends so that they could tolerate the NET. Being known, understood, and encouraged was crucial. During NET, care needs increased and were often reduced afterward, but aftercare was still needed.

> *"I would say, without support, do not start, because then it has too much impact. She (nurse) came twice a week, but, now, she comes once in two weeks."* Female, aged 48.

> *"Being able to discuss things I encounter during therapy, I really needed that."* Female, aged 43.

Quality of Life and Global Functioning

Eight participants who benefitted from NET reported an increased quality of life. Examples are feeling liberated, being more open, positive thinking, finding hobbies, allowing domestic help for oneself, handling things better, putting things in perspective with less worrying, and trying to pick up life again.

> Before therapy: *"I felt alone in the world." During therapy: "I started to think about myself differently." After therapy: "I enjoy life more; it doesn't always have to go bad, and it can also go well. I have new friends; we do a lot together. It took a long time before I really trusted in someone."* Male, aged 56.

> After therapy: *"What's really important is that I've started to allow myself more [...]. I allow myself at some point in the day to pick up a book and sit down to read or go to the village. I buy flowers and put them in a vase. Before, I wouldn't allow myself to buy flowers while I longed for it. I have allowed myself an aquarium that had been on my wish list for decades [...]. Yeah, that's just something for myself that I'd like to have."* Female, aged 52.

Four participants who were minimally benefited or were not benefited from NET told about fewer "bad days," living by the day, standing alone, feeling minimally good in being social, continued getting angry, missing adequate support, still having difficult days, and, sometimes, nothing was changed:

> During therapy: *"I allow myself to feel bad!" After therapy: "My head has calmed down. I can put things into perspective and look back more relaxed."* Female, aged 46.
>
> After therapy: *"My life hasn't changed. I find that very unfortunate. I would have liked that different, but it remains difficult."* Female, aged 45.

Mixed methods results

The comparison of the quantitative results based on diagnostic tools and qualitative participants' experiences was focused on similarities and differences for post-traumatic stress disorder, dissociation, severe mental ill symptoms, care needs, quality of life, and global functioning (Table 3).

Post-traumatic stress disorder symptoms (CAPS-5)

Congruence was found in sixteen participants. These were participants who were in (partial) remission (n=11) and those who were not in remission (n=5). (Partial) incongruence was present by perceiving slight improvements (n=3) and was present in two participants in remission according to the quantitative results, who expressed persistent symptoms. One participant expressed improvement, while there was hardly any change in post-traumatic stress disorder symptoms (n=3).

Dissociative Symptoms

Thirteen participants mentioned dissociative symptoms. Congruence was found in experiencing reduced dissociative symptoms (n=5) and in remaining dissociative symptoms (n=7). Incongruence was present in one participant: dissociation was still present based on the DES, but the experience was different because "chaos is gone."

Severe Mental Ill Symptoms

Congruence in severe mental ill symptoms was found in perceived reduced symptoms (n=11) and when there are no changes (n=5). (Partial) incongruence was present in perceived improvement, but not in quantitative scores symptoms (n=7). In two persons, quantitative measures were improved, but they perceived no changes in symptoms.

Care Needs

In eighteen participants, congruence was found in perceiving no change in care needs (n=11) and less care needs (n=7). (Partial) incongruence consisted of improvement in CAN scores, but perceived care needs did not change (n=3). In one participant, CAN scores decreased and increased over time, but perceived care needs diminished.

Quality of Life

Congruence (n=15) was present in perceived better quality of life (n=10) and in others who did not perceive changes (n=5). Partial congruence consisted of perceived improved quality of life (n=5). Two participants perceived no changes in quality of life, but MANSA scores improved.

Table 3 Congruency between quantitative and qualitative data

Quantitative assessment			One-to-one analysis of improvement during treatment period based on			Congruence	
	Change of score, relative to baseline[1]	N	Quantitative instruments	Qualitative interviews		% (p-value)[2]	Kappa (95% CI)
			Improved	Yes	No		
Primary outcomes							
PTSD	- 35%***	22	Yes	11	3	73%	0.41
			No	3	5	p=0.07	(0.02 to 0.81)
DES	- 25%***	13	Yes	5	0	92%	0.84
			No	1	7	P=0.005	(0.55 to 1.00)
Secondary outcomes							
HoNoS	- 19%**	22	Yes	8	3	59%	0.18
			No	6	5	p=0.33	(-0.21 to 0.58)
CAN	- 3%	22	Yes	7	1	82%	0.63
			No	3	11	p=0.005	(0.30 to 0.95)
MANSA	+1%	22	Yes	10	2	68%	0.43
			No	5	5	P=0.11	(-0.04 to 0.72)
GAF	+8%***	22	Yes	12	2	68%	0.25
			No	5	3	P=0.23	(-0.16 to 0.66)

[1] Difference of score between T2 versus T0, based on the quantitative strand of this mixed methods study; ***p<0.01, ** p<0.05, * p<0.10, two-sided

[2] P-values (one-sided) obtained from Fisher exact test.

Global functioning

Congruence (n=15) was present in perceived global functioning (n=12) and in others who did not perceive changes (n=3). Partial congruence consisted of perceived improved global functioning (n=5). Two participants perceived no changes in quality of life, but GAF scores improved.

Congruency of the qualitative and quantitative results

Table 3 summarizes the congruency between qualitative and quantitative assessments of study outcomes. Most outcomes were assessed in n=22 subjects, DES in 13/22 persons. The scores decreased significantly with 25–35% for the two outcomes: PTSD and DES, whereas they changed less or did not change significantly for the other outcomes. Experienced improvement reported in the interviews was related to the changes assessed by the quantitative measurement instruments. Congruency was highest (> 73%) for PTSD, dissociative symptoms (DES), and CAN, but not for SMI (HoNoS), quality of life (MANSA), and global functioning (GAF). Cohen's kappa was statistically significant for the qualitative and quantitative symptoms of the clinical characteristics PTSD and dissociation as well as for CAN.

Perceived support and relation with narrative exposure therapy results

Qualitative findings

Ten out of 11 participants who were in remission for posttraumatic stress disorder perceived the professional and informal support as sufficient to very good.

> "*I got enough support from the nurse. She helped me with tips for insomnia, reassured me by saying 'this will pass'. She helped me to continue the therapy because I hesitated. I could talk about it with her and that helped. I see her as a buddy." "My husband listened to me and my children knew what I was doing. I also received a lot of support from my boss.*" Female, aged 43.

Six participants, who were not in remission, received less support during NET because of insufficient professional or informal support.

> "*I am disappointed with the mental health institute; I needed help but had doubts to ask for help. My supporter left the institute unexpectedly; he did not even say good bye! Therapy was good, but aftercare was needed and not given." "I found support from fellow patients*." Female, aged 51.

Five participants not in remission experienced insufficient care during and after NET. For some patients, it was not possible to contact the mental institute when needed; others had no support from the FACT during NET, and some did not get aftercare.

> *"I called the crisis service, but I was not on the list. They advised to call the General Practice. I found that difficult, if you don't get help, then you have to call a GP?"* Female, aged 28.

> *"I couldn't handle traveling by taxi, and there was no support organized by the therapist."* Female, aged 63.

In addition, they had no (adequate) support from close relatives, friends, or residential caregivers.

> *"My parents are not interested; they only speak of themselves. They never say: 'I love you.' I feel misunderstood by people."* Female, aged 28.

> *About residential caregivers: "They can't really do anything for me other than just talk; it doesn't solve the problem."* Female, aged 27.

Pairwise analysis of support and remission

Clinical remission of PTSD, assessed by the diagnostic instrument, was strongly related to perceived support during the treatment period (Table 4). All the patients who perceived sufficient to very good professional and informal support (10/10) were in remission at T2 (quantitative assessment). Among

Table 4. Association between experienced support during NET and remission of PTSD

Remission PTSD at T2 (PTSD questionnaire)	Experienced support (interviews)		
	Sufficient to very good	Insufficient or not	N
Yes	10 (100%)	1 (9%)	11
No	0	11	11
Total	10	12	22
Difference between 100% and 9% statistically significant p<0.0001 (one-sided, Fisher exact test)			

the 12 patients who experienced less or no support, only one (9%) was in remission ($p < 0.0001$, Fisher exact test).

6.6 DISCUSSION

To our knowledge, this is the first mixed methods study investigating the efficacy and the experiences of NET in outpatients with SMI with comorbid PTSD receiving community mental healthcare in flexible assertive community treatment teams. The results of the qualitative and mixed methods analysis indicated that the participants lived with PTSD for many years. The most frequently mentioned symptoms included avoidance, intrusive thoughts, nightmares, anxiety, depression, suicidality, and low physical health. Receiving NET was an intensive experience but was mostly bearable. During NET, most of the participants experienced fewer symptoms. Perceived posttraumatic stress disorder and dissociation decreased, leading to slight improvement in quality of life. After NET, two-thirds of the participants perceived less of these symptoms. The main expressed care need was appropriate support to tolerate NET. Being known, understood, and encouraged was crucial. The participants who benefited from NET experienced increased quality of life and functioning. Those who did not benefit, often lacking proper care support, were less good at being social, and experienced more negative emotions.

The mixed methods results showed that the qualitative experiences were congruent with diagnostic scores for PTSD, dissociative symptoms (DES), and CAN ($p < 0.05$, one-sided). Some participants perceived improvement with respect to SMI symptoms, but this was not congruent with the scores of the HoNOS (Table 3). In the quantitative analysis, however, SMI symptoms as assessed by HoNOS were significantly reduced after NET (Table 2). The participants who indicated that they experienced sufficient support were more often in remission than those who did not experience support. Qualitative experiences for quality of life and global functioning were not congruent with quantitative scores (MANSA and GAF).

Results in context

The participants in this study experienced NET as intense, but most of them were able to tolerate it and completed the therapy. Until recently, NET was not offered to outpatients with SMI with comorbid post-traumatic stress disorder, because many mental health practitioners and researchers were convinced that TFT like NET for these vulnerable patients would not be tolerated. Moreover, as is the case in most studies concerning TFT, NET studies often excluded patients with psychotic disorder, bipolar disorder, substance misuse, and severe suicidal ideations [15, 39-41]. This exclusion is often based on the clinical perception of vulnerability in patients with SMI, which is long-standing and

resulted often in inappropriate psychiatric care, such as avoidance of trauma and overly caring behavior and leads to under-treatment [19]. A recent meta-analysis of TFT for post-traumatic stress disorder in patients with SMI has shown that PTSD treatments had a large effect on PTSD outcomes. Still, it was also concluded that patients with SMI often do not receive evidence-based TFT [42]. Unfortunately, resilience is still underestimated in outpatients with SMI [43] and also in patients with post-traumatic stress disorder [44].

Symptoms

This study showed that NET is clearly efficacious in outpatients with SMI with comorbid post-traumatic stress disorder and dissociation. Qualitative findings confirm these results and also clarified which trauma symptoms bothered participants the most. In the Netherlands, Routine Outcome Monitoring for patients with SMI is periodically performed with the HoNOS for severe mental ill symptoms, CAN for care needs, and MANSA for quality of life. These instruments were used for SMI, but outcomes were hardly significant for SMI or care needs and quality of life in this group [19]. Qualitative results confirm that severe mental ill symptoms decreased slightly and that care needs hardly changed, but the participants mentioned other specific care needs, and quality of life slightly improved.

One can question if these instruments are responsive enough to evaluate the treatment effect on severe mental indicators. Because this population has different symptom burdens, generic measuring instruments are not distinctive enough to see the specific effects of treatment. Disorder-specific measures have the most precise responsiveness for individual treatment and are recommended for clinical use [45]. Therefore, a structured diagnostic interview, such as the M.I.N.I.-plus [46], provides more precise information for different psychiatric diagnoses and is also suitable because of generic items, such as substance abuse.

The importance of adequate professional and informal support

Outpatients with SMI with comorbid post-traumatic stress disorder are vulnerable, but they can tolerate exposure if there is sufficient informal and professional support. It was striking that those who actually experienced informal social support and adequate professional support were able to benefit more from NET than those who missed adequate informal or professional support or both. In some cases, it turned out that the protocol agreement to offer support at least every two weeks was not kept. It is, therefore, clear that careful adherence to the treatment protocol must be maintained.

Social relationships play a crucial role in recovery from trauma [47], and high informal social support may protect against the negative effects of PTSD [48]. Mueser et al. [49]) also argued that traumatized patients with SMI who received social support have a better course of illness, which can minimize the effects of stress [49]. Furthermore, positive support can provide a foundation for resilience because it reduces stress levels, depression, and (severity of) post-traumatic stress disorder [44]. Our study confirms these results because there was a clear link with adequate informal and professional support and the effect of NET. Flexible assertive community treatment team members in this study provided psychiatric supportive care and also, often, social support, especially in the patients who hardly had a social network.

Strengths

The *first* strength of this study was that it was conducted in the real-life clinical context. As a result, there is less chance of overestimating the effect of the intervention. *Second*, NET was provided by trained and certified therapists, who were all FACT team members and, therefore, familiar with patients with SMI. *Third*, NET fitted well in the workflow of the involved professional, which is helpful for future implementation. *Fourth*, quantitative results were firm, despite being a small group [19]. *Fifth*, the qualitative analysis based on QUAGOL stages was done very thoroughly and included peer debriefing, transparency, reproducibility, and triangulation. Based on feedback from all the authors, constant comparison and thematic analysis were undertaken. *Sixth*, after 22 interviews with enriching data, saturation was reached. *Seventh*, the mixed analysis showed the important correspondences and differences between quantitative diagnostic results and participants' perceptions. Congruence and incongruence were both present, reflecting daily clinical practice. *Eighth*, the relationship between supportive care and being able to benefit from NET was convincing. Lastly, this mixed methods design gave more in-depth knowledge and insights.

Limitations

The *first* limitation of this study is that the results were based on a small group of patients, which restricts generalization and holds especially true for the few men who participated in the study. *Second*, there was no control group; therefore, the results may not point at a causal effect of NET. *Third,* flexible assertive community treatment team members selected patients with possible post-traumatic stress disorder from their own case load, who could potentially benefit from NET. This may have led to selection bias and reduced representativeness for the entire population in flexible assertive community treatment teams. Therefore, screening for trauma exposure and post-traumatic stress disorder was carefully performed with appropriate instruments: LEC-5 [50] and PCL-5 [51].

Implications

This study shows that outpatients with SMI with comorbid posttraumatic stress disorder can be treated well with NET and that this therapy was highly applicable in this sample of patients with SMI. Although it was a small study population, results were convincing. Given the similarities with other TFT, it is plausible that NET can also be offered to patients with SMI [11, 42].

Patients with SMI and comorbid post-traumatic stress disorder often have a history of abuse and neglect, both in the family of origin and by mental healthcare providers based on incorrect assumptions [2, 11, 52, 53]. Actual severe mental ill symptoms hinder to assertively ask for adequate help. Moreover, most of the patients with SMI also have comorbid somatic disorders related to the side effects of psychotropic drugs and an unhealthy lifestyle, which possibly reinforces further social marginalization [54, 55]. These factors can also lead to pharmaceutical undertreatment or overtreatment [56]. To counteract this, regular screening of present post-traumatic stress disorder, other comorbid mental disorders, drug use, and somatic disorders is necessary. Simultaneous adequate care support is an important condition for the effectiveness of the entire treatment and promotes resilience. During intensive therapies such as NET, more support is needed than usual in this specific group.

6.7 CONCLUSION AND RECOMMENDATIONS

In our study, NET is clearly efficacious in outpatients with SMI and comorbid post-traumatic stress disorder. TFT such as NET should certainly be actively offered to this specific vulnerable population, because the prevalence is high, and chronic trauma related symptoms negatively affect the main disorder and overall functioning. In addition, it is important that the resilience of patients with SMI is not underestimated, but optimal professional and informal support are necessary to strengthen this resilience. Therefore, prior to intensive trauma treatment and in consultation with the patient, it is recommended to involve professional and informal care givers. Training and equipping flexible assertive community treatment team members are also recommended, especially for nurses, who often have intensive contact with patients with SMI and usually are the first to observe changes during NET on which they can give quick and adequate care support. Because this was a small group with no control, in the future, a controlled study on NET with patients with SMI is recommended.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.804491/full#supplementary-material

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Antoinette: ‘Meta was like an arm around my shoulder, protecting me in the world.

She radiated warmth and calm. If you were bound then, she gave you freedom.

She was like an angel: no matter how dark it was, she brought light’.

De woestijn zal bloeien. Inspiratie voor geestelijke verzorging in vernieuwing in de psychiatrie, Meta Top & Arend Jan Waarlo (red), 2017

In memoriam Meta Top, 1956-2016 verpleegkundige en geestelijk verzorger.

Chapter 7

General discussion

7 INTRODUCTION

Severe Mentally Ill (SMI) patients often have experienced traumatic events and as a result may develop comorbid posttraumatic stress disorder (PTSD). In clinical practice, trauma exposure and PTSD had not been recognized for a long time and therefore hardly were noticed with for instance, no information found into SMI patients' records. This meant that no targeted diagnosis was made, let alone an appropriate treatment program.
This thesis aimed to study the relevance of PTSD in SMI patients and to improve the treatment of PTSD in these patients in clinical practice. This was conducted by a systematic review of the prevalence of interpersonal traumatic experiences and PTSD in SMI patients (Chapter 2), a practice-based case study on the treatment of a patient with Complex PTSD using a three-phase treatment modality (Chapter 3), and by the design and conduct of a mixed method study (Chapter 4), consisting of a quantitative strand (Chapter 5) and a mixed qualitative-quantitative strand (Chapter 6).
This discussion section summarizes the main findings of the studies (7.1), followed by their interpretation (7.2), and the methodological strengths and limitations (7.3). Subsequently, the implications of the research for clinical practice are discussed (7.4), leading to the overall conclusion with the answers to the research questions (7.5).

7.1 Summary of the main findings

Prevalence of interpersonal trauma exposure and trauma-related disorders in SMI (Chapter 2)
Trauma exposure and posttraumatic stress disorder (PTSD) are hardly recognized in clinical practice. Our review of 33 included studies showed that SMI patients often have experienced traumatic events and subsequent may develop PTSD. In SMI patients, population-weighted mean prevalence rates were high: physical abuse 47% (range 25-72%), sexual abuse 37% (range 24-49%), and (PTSD) 30% (range 20-47%). Compared to men, women showed a higher prevalence of sexual abuse in schizophrenia, bipolar disorder, and mixed SMI diagnosis groups. The prevalence rates of interpersonal trauma and trauma-related disorders were significantly higher in SMI than in the general population. Emotional abuse and neglect, physical neglect, PTSD, Complex PTSD, and dissociative disorders have been scarcely examined in SMI. Traumatized patients with SMI show more severe symptoms and a worse course of illness than non-traumatized patients with SMI.

Phase Based Treatment of a complex SMI case involving Complex PTSD and psychosis related to Dandy Walker Syndrome (DWS) (Chapter 3)
In clinical practice, trauma focused therapy is often considered hard to endure for SMI patients with psychosis and (CPTSD) due to repeated childhood trauma exposure. Therefore, a phase-oriented treatment method commonly used at the time, including (1) stabilization, (2) trauma focused therapy, and (3) integration of personality with recovery of connection was proposed. This was illustrated by a case study of a 47-year-old woman with psychosis due to DWS. Stabilization included psychiatric nursing care and stabilizing group treatment. After stabilization, symptoms showed improvement: self-regulation, assertiveness, and negative cognitions decreased. Prolonged imaginary exposure was effective and included narrative writing assignments and a closing ritual. This intensive multidisciplinary, phase-based approach proved effective and CPTSD turned out to be in full remission.

Social integration and recovery improved, and polypharmacy decreased. Conclusion was that a phase-based treatment approach with multidisciplinary collaborative care was effective in this case.

Narrative Exposure Therapy for PTSD associated with repeated interpersonal trauma in SMI patients: a mixed methods design (Chapter 4)

Following the case study, we hypothesized that SMI patients with (C)PTSD can endure trauma focused therapy (TFT). In 2012, Narrative Exposure Therapy (NET) was introduced in our clinical practice. NET has been shown to be effective for various vulnerable patient groups with repeated interpersonal trauma. At the time some Flexible Assertive Community Treatment (FACT)-team members experimented with provided NET for SMI patients with comorbid PTSD. They found promising results in clinical practice, but without scientific basis because NET had not been specifically studied in SMI patients. Based on these positive clinical results, we decided to focus on further research on NET in SMI. Therefore, a mixed methods convergent design was developed consisting of quantitative repeated measures and qualitative semi-structured in-depth interviews based on Grounded Theory.

Treating SMI patients with Narrative Exposure Therapy for comorbid PTSD (Chapter 5)

In this mixed study a population of twenty three participants, nineteen were women and the mean age was 49.9 years. The mean PTSD duration was 24.1 years. Quantitative results were based on the CAPS-5, DES and SMI indicators. PTSD severity decreased from 37.9 at the start (T0) to 31.9, after NET (T1), and decreased further to 24.5 at follow up (T2). Dissociation, SMI symptoms, duration of contacts, and even the use of medication decreased. Global functioning increased, but quality of life and perceived needs did not change. Eleven participants were in remission for PTSD at T2, of which five were also in remission for major depressive disorder.

Investigating efficacy and experiences with NET in SMI patients with comorbid PTSD receiving FACT: a mixed methods study (Chapter 6)

Qualitative findings showed that after NET 18 out of 23 participants perceived less symptoms. Mixed analysis showed further substantial congruency between quantitative scores and participants' perception of PTSD, dissociative symptoms and care needs (Cohen's kappa>0.4). Remission of PTSD was associated to sufficient experienced support. Conclusions were that SMI patients experienced NET as intensive, but most of them tolerate it well. This therapy is clearly efficacious in this group.

Summarizing, this thesis describes the results of the prevalence review which showed that exposure to interpersonal trauma and trauma related disorders are very common in patients with SMI. The case study learned that SMI patients can successfully be treated with trauma focused therapy, which was done in the context of phase based treatment. The mixed study demonstrated with quantitative results that PTSD and SMI symptoms were reduced in a group of SMI patients, who are treated with NET. Qualitative findings showed that participants experienced NET as intensive, and most of them tolerate it well. The mixed methods results showed that patients' experiences were largely congruent with diagnostic instruments. Perceived professional and informal support was related to remission, and was a key factor for the success of NET in SMI patients. Conclusions were that SMI patients experienced NET as intensive, and most of them tolerate it well. This therapy is clearly efficacious in this group.

7.2 Interpretation main findings

Interpersonal trauma exposure and SMI

An important finding in our study was that interpersonal trauma and trauma-related disorders in SMI patients are often not recognized in clinical practice. The results of our prevalence review were overwhelming, because more than forty percent of SMI patients were exposed to multiple forms of abuse for a long time (often both in childhood and adulthood), and PTSD was present in third of the SMI population. Remarkable, in our study we found that emotional abuse and neglect, and physical neglect were hardly researched at the time [1]. Our review further showed that female participants reported significant higher frequencies than males for childhood sexual abuse by adults (48.4% vs. 23.7%), childhood sexual abuse by peer (39.3% vs. 19.4%), adult sexual abuse (38.3% vs. 15.4%), and domestic violence (59.3% vs. 36.6%).

PTSD diagnosis (49.6%) was based on using structured interviews: SCID-PTSD [2] or CAPS-IV [3] in 19 studies and 14 studies used checklists such as [4]. Lu et al. 2022 [5] presented in a recent study among SMI patients (n=536) in community mental health care even higher prevalence of at least one traumatic event (92.4%), and met criteria for probable and provisional PTSD (49.6%). These rates are high and often based on multiple abuse [5]. Using the structured CAPS-5 possible explains the higher rates of traumatic events and PTSD compared to CAPS-IV and checklists such as the PCL-5 in our study [6].

In conclusion, the prevalence of trauma exposure and PTSD are very high in SMI, which is significantly higher than those of the general population, where epidemiological studies reported the lifetime PTSD prevalence rates of 13-20.4% for women and 6.2-8.2% for men [7].

These findings are important for clinical practice: SMI patients should be regularly screened for exposure to current violence. In this way, previous and present experienced trauma exposure and PTSD can be detected more quickly, and appropriate treatment can be initiated.

The relation between childhood trauma exposure and SMI in adulthood

Childhood trauma (emotional, physical, and sexual abuse, emotional and physical neglect) appears an independent risk factor for adulthood victimization in SMI [8]. Stoltenborgh et al. (2013) [9] investigated that child physical neglect prevalence rates were 163 out of 1,000 and emotional neglect rates were 184 out of 1,000 with no gender differences. The authors state: “that child neglect is a problem of considerable extent, but seems to be a neglected type of maltreatment in scientific research” [9]. People with a history of childhood neglect are at risk to develop mental and physical illness. Since our review (chapter 2), some studies have addressed child abuse and neglect in relation to SMI and PTSD [10-12].

In these studies, it is clear that childhood physical and emotional neglect, and emotional abuse, also have serious consequences for risk of developing severe mental illness such as Schizophrenia Spectrum Disorder, Bipolar Disorder, Major Depressive Disorder, and chronic PTSD. Moreover, the physical illness burden is also much larger than in the general population [12]. Based on these findings, prevention and detection of childhood trauma are highly important.

Patients with SMI who reported experiences of childhood maltreatment, were two to five times more likely to report domestic and sexual violence victimisation in adulthood. These associations held for each of emotional, physical and sexual childhood abuse [8]. As result these patients often were traumatized again.

In line with our prevalence study, childhood trauma is further specifically related to the development of SMI. Choi, Choi et al. [13] (2015) found that childhood physical (40.5%), emotional (37.3%), and sexual abuse (31.7%) is related to psychotic symptoms. In addition, individuals reported two types of abuse (14.3%), and individuals reported all three types of trauma (19.8%). Implications are that childhood maltreatment is significantly associated with chronic PTSD symptoms and the likelihood of psychotic symptoms [13].

Childhood trauma and psychosis have also a dose–response relationship [14]. There is further evidence of childhood trauma and (high risk for) psychosis, increased frequency of affective symptoms, substance use, and worse functional impairment [15]. Childhood trauma is also a risk factor for developing bipolar disorder, with a more severe clinical presentation over time with an earlier age at onset and an increased risk of suicide attempt and substance misuse [16]. Exposure to childhood and young adulthood trauma during neurodevelopmental stages earlier in life, contributes to an increased risk of developing bipolar disorder [17].

SMI patients with mood disorders experienced higher rates of traumatic life events in childhood. Two most reported trauma types were emotional abuse 59.1% and physical neglect 54% were reported in this group [18]. Emotional and sexual abuse in childhood were significantly associated with a higher symptom severity in chronically depressed adults. Results showed that multiplicity was the significant predictor for symptom severity in chronically depressed patients [19].

Trauma exposure and PTSD in SMI

It is demonstrated that SMI patients without trauma exposure have less disease burden compared with SMI patients with trauma exposure [6]. However, there is still underreporting of trauma exposure. As a result, PTSD that may be present will not be detected. For these patients this also means that PTSD is not treated. In the meantime, it is known that trauma focused treatment for comorbid PTSD in SMI patients is tolerated and effective. In line with our results, present SMI symptoms reduced after trauma focused therapy and qualitative outcomes increased [20, 21].

Trauma exposure and SMI are further intertwined in two ways: (1) individuals can develop SMI after being exposed to trauma in their childhood, and (2) individuals who develop SMI also have a higher risk of experiencing violent victimization [5].

In schizophrenia spectrum disorders comorbid PTSD is often ignored and unexplored, despite a possible impact on its symptomology. Dallel, Cancel et al. (2018) [22] conducted a systematic review with 38 studies about the prevalence of PTSD in schizophrenia spectrum disorders. Results showed that the range of prevalence of PTSD was between 0% and 55%. However, the authors concluded that 79% of the studies found a prevalence of PTSD superior to 10% [22]. Our prevalence results based on seven studies found a higher prevalence of PTSD rates in schizophrenia spectrum disorders (30%). This is probably an overestimation compared to this much larger study. Buswell et al. (2021) [23] stated that there is a lack of published research on first episode psychosis, psychotrauma, and PTSD. Psychotic symptoms are often very threatening and can lead to PTSD. Results suggest that prevalence rates of psychosis-related PTSD have not reduced over the past decade despite ambitions to provide trauma-informed care [23].

The prevalence of PTSD among patients with bipolar disorder ranged from 4% to 40%, with women and those with bipolar-I versus bipolar-II disorder experiencing higher prevalence of PTSD. The prevalence of bipolar disorder among individuals with PTSD ranged from 6% to 55%. Patients with co-occurring bipolar disorder and PTSD, experienced high symptom burden and low quality of life. No studies evaluated prospective treatment of patients with co-occurring bipolar disorder and PTSD [24].

The high prevalence of major depressive disorder and PTSD comorbidity is well established, with comorbidity rates often between 30 and 50%. Major depressive disorder with comorbid PTSD disorders showed greater social, occupational, and cognitive impairment. Patients who experience higher levels of distress are at increased risk of suicide. Prognosis is poor when the two disorders co-occur and treatment dropout is more common [25]. The treatment for PTSD in SMI is still underrepresented in the literature. However, trauma focused therapies are effective in SMI patients [21, 26].

Prevention in children

Traumatized children have fewer opportunities in their lives. Intergenerational transmission on abuse is consistently found in child maltreatment. Buisman et al. (2020) [27] suggest that including multiple informants (family members) may be necessary to obtain more valid estimates of intergenerational transmission of child maltreatment [27].

In the Netherlands, the overall prevalence estimate of child maltreatment in 2017 was 26–37 per 1000 children. The most important risk factors for child maltreatment were: low parental education, parental unemployment, immigrant status, and single parenthood. Neither prevalence rates nor risk factors changed significantly between 2005, 2010, and 2017. Finally, in 46 % of the reported families, child maltreatment occurred in a context of domestic violence [28]. This means that any given time per year, approximately 31 juveniles per 1000 are abused and/or neglected. Beside, according to the National Reporter on Trafficking in Human Beings and Sexual Violence against Children, the size of the number of victims of sexual violence (both within and outside the family) is much larger: one in ten girls, had manual sex and 5% to 10% have experience with unwanted oral sex or sexual intercourse [29].

In young people trauma exposure and PTSD are associated with complex psychiatric symptoms, and high risk for significant impairment. Improved screening, reduced barriers to care provision, and comprehensive clinical assessment are needed to ensure that trauma-exposed young people and those with PTSD receive appropriate treatment [30-32].

Phase-Based Treatment for Complex PTSD

In 2009, our institute started in clinical practice with the Stabilizing Group Treatment: “Before and beyond” for SMI patients with Complex PTSD (CPTSD). The participants spoke for the first time about their trauma’s and were given tools to deal with their symptoms. This provided more skills and relief [33, 34]. In one female member, psychotic disorder and comorbid CPTSD were both present. At that time, trauma-focused therapy was not provided, because the belief was that patients with early childhood trauma and psychosis could not tolerate this type of therapy. As a result, trauma-focused therapy had not been performed. After stabilizing group treatment, in consultation with the patient and the treatment team, it was decided that she would get prolonged exposure therapy, which was effective. As a result social functioning and recovery improved, and polypharmacy decreased. Since, there has been an ongoing debate about the usefulness and necessity of Phase Based Treatment such as “Before and beyond” or Skills Training in Affect and Interpersonal Regulation (STAIR) for CPTSD [35]. De Jongh et al. (2016) [36] argued that there is no rigorous research to support a phase-based approach for positive treatment outcomes for adults with CPTSD. Trauma-focused treatments have not unacceptable risks in adults with CPTSD, and patients can profit significantly from trauma-focused treatments without preceded by a stabilization phase [36]. Hoeboer, de Kleine et al. (2021) [37] showed that CPTSD is associated with more severe PTSD and with higher comorbidity. CPTSD did not

predict treatment outcome and did not indicate differential treatment outcome of Skills Training in Affect and Interpersonal Regulation (STAIR) and prolonged exposure [37].
This suggests that phase-based therapy is not necessary for CPTSD. Cloitre (2021) [38] stated that trauma-focused intervention is the most successful treatment option for PTSD symptoms, but expected that as compared to PTSD, CPTSD may require a longer course of treatment and/or benefit from a greater diversity or type of interventions which include a focus on disturbances in self-organization. The results also showed the need for adaptations and tailoring of interventions based on ongoing stressors, chronic trauma, chronic PTSD, and childhood trauma [38].
Using personalized stabilizing specific interventions can still meaningful [33, 34]. This is in line with our clinical practice, where nurses provide individual stabilizing interventions in an eclectic way: before, during, and after trauma focused therapy. The goal is to reduce complex symptoms based on the patient's specific needs, such as sleep problems, dissociation, emotion regulation, negative cognitions, or promoting physical health.
The following standards of care are valuable to provide appropriate treatment and care: General Severe Mental Illness module [39] and specific standards such as the standard of Psychotrauma- en stressor related disorders [40] and the standard for Dissociative Disorders [41, 42].

Narrative Exposure Therapy

Quantitative results

SMI patients with comorbid PTSD have often experienced multiple trauma and this led to the indication for NET. Until now, NET was barely provided in SMI outpatients because of their presumed vulnerability. As participants in our study lived with PTSD for many years (mean 24,1, SD 14.5), it is very promising that 11 of 21 participants who completed NET were in remission for PTSD at follow up, and five of them were also in remission for Major Depressive Disorder. Moreover, dissociation, SMI symptoms, duration of contacts, and medication decreased, whereas global functioning increased.
In other words: “it's never too late to seek therapy”. It is therefore important that practitioners are well informed about treatment options. They can motivate SMI patients with PTSD for appropriate treatment. Our main quantitative results are in line with other controlled NET studies with vulnerable patients for instance PTSD patients living in instable situations, older, and depressed patients [43].

Qualitative results

As was demonstrated in our study, receiving NET was an intensive experience, but was bearable for our SMI patients. Participants told that NET-therapists put them at ease and reassured them during NET. The therapists were flexible when participants had to cancel the appointment, or kept the session a bit shorter if it became too much for the participant. They also used humour to make the session less difficult to bear. During and after NET most of the participants reported fewer PTSD symptoms such as: intrusions, nightmares, fear, anger, avoidance, vigilance, and dissociation. SMI symptoms decreased with depressive symptoms improved with half of the patients in remission. Psychotic complaints decreased and that led to a better quality of life.
A recent qualitative study aimed to explore patients’ and therapists’ experiences with trauma-focused treatments (EMDR) in patients with PTSD from childhood trauma. Semi-structured interviews were conducted with patients (n=44) and therapists (n=16). Thematic analysis was used to identify key themes within the data. The emerged themes included the importance of the patients’ willingness to engage and commit to the treatment process. The trauma work produced changes in insight and sense of self, and empowerment for the future. The willingness to engage and commit to the treatment

process was improved. These changes of insight are in line with our study, no matter how hard it was sometimes for patients, adherence to therapy remained high. In addition, therapists made similar suggestions for optimising the therapist role in the trauma-focused treatment [44].

Professional support

Our qualitative results showed that involved nurses and social workers had a crucial role in supporting participants during and also after NET. Participants had the experience that they were known, understood, and encouraged, which was very helpful for continuing the NET. Participants indicated that without this support, NET would not had been be well tolerated or would even be discontinued. The same was the case in reverse: some participants who did not benefit from NET, perceived lack of good care from nurses and social workers. These findings show that it is important for nurses and social workers who do not conduct trauma therapy themselves, need to be given the opportunity to become proficient in skilled trauma-oriented care. In that way, they will understand the process the patients go through in trauma therapy and will have better understanding in the need for the patients of support.

Informal support

The participants in our study had different sources of informal support such as close relatives (spouse, partner, children, and parents), good friends, neighbours, colleagues, churchgoers, and fellow patients. Informal support included listening, comforting, distracting, making music, doing fun things together, offering practical help such as housekeeping, and grocery shopping. Some participants received hardly any informal support from close relatives. These patients were mainly supported by professionals. For them it is important that professionals help them to participate in society. Van Spronsen and van Os (2021) [45] stated that: “patient autonomy, awareness and co-creation are important topics”. Based on professional and experiential knowledge, the authors emphasize the importance of an equal relationship between patient and professional. In addition, a lot of work could done together in groups with patients and psychiatric professionals networks within mental health care and beyond [45]. This will be helpful especially for the patients with a poor social network.

Narrative Exposure Therapy in SMI

SMI patients with comorbid PTSD have not been treated for PTSD for a long time. The belief was (and sometimes still is), that these vulnerable patients would not tolerate trauma-focused therapy. Van den Berg et al. 2015 [26] has shown that Prolonged Exposure and EMDR protocols are effective, safe, and feasible in patients with PTSD and severe psychotic disorders, including current symptoms [26]. NET is also an exposure based therapy and efficacious and applicable in SMI patients with repeated traumatic events throughout the life course. They can benefit from chronology and the testimonial character. In the mixed methods study, the importance of appropriate informal and professional support was an important condition. The result was that NET could be better tolerated.

The value of the life story

After many years not being able and not allowed to speak about what had happened to them the participants in this study were allowed to share their unique, often painful experiences with their therapist. Starting with NET was often terrifying, and it took courage to lay the lifeline. This was done in a chronical order with positive events symbolized by flowers and traumatic events by stones. The procedure immediately gave an overview of their lives so far, which was often hard to do and not easy,

but at the same time it also gave recognition: “this happened in my life”. The following sessions focused on exposure of traumatic events based on the lifeline. Flowers were given attention so that the good events in life were not forgotten. During the last session, the life story was read aloud where witnesses could be present, such as close relatives, friends and professional supporters [46]. During NET, participants could now spoke out and talk their life story being believed, without the risk of being silenced and rejected. Participants who were in remission for PTSD, experienced more order in their “head”. They indicated after NET, that the chaos diminished and brought more order in daily life.

7.3 Strengths and limitations

Prevalence review

The results of our thorough prevalence review were based on four different databases and data were independently extracted by three reviewers. Other reviews on SMI and PTSD published after 2013 did not point at important gaps in our review. Although we may not have captured all studies, it is likely we have captured the most relevant ones. Despite this exhaustive search strategy, an unambiguous set of search terms was not available to cover such a long time period. In most studies of our review, the SMI diagnoses of patients were confirmed by structured interviews. Nevertheless, trauma exposure, SMI and PTSD were assessed by many different instruments with regard to life stage and type of interpersonal trauma, which limits comparability of the prevalence rates across the studies. Nowadays, based on the DSM-5 or ICD-11, psychotrauma and PTSD can be searched in a more standardized way.

Case study

The case study in this thesis was highly specific and therefore hardly generalizable in a scientific sense. Nevertheless, it illustrated the contemporary views on phase-base treatment of trauma at the time. Relevant trauma scales were used before and after treatment for CPTSD based on the Structured Interview for Disorders of Extreme Stress (SIDES) [47], and assessment of exposure treatment for PTSD was based on the Davidson Trauma Scale (DTS) [48].

Mixed methods study

First, the study protocol of the mixed methods convergent design facilitated the ethical approval by the Committee on Research Involving Human Subjects, Arnhem-Nijmegen (number 1843-2015) [49]. Second, the mixed methods used different independent data sources: quantitative data consisted of repeated measurements based on structured interviews, routine outcome measures, use of medication, the number and duration of therapeutic contacts based on electronic record data, and the qualitative data consisted of semi-structured interviews. Third, the interviewer who conducted the semi-structured in-depth interviews, was not involved in the quantitative data collection. Fourth, quantitative and qualitative data were first independent analysed, and then the mixed methods analysis was done for each participant. Fifth, prior to the study, fifteen therapists were trained in trauma diagnostics with the CAPS-5 and NET. Five of them were involved in the study. The result was further that NET was implemented in the whole mental health institute in different patient groups.

Limitations of this study were related to methodology and the conduct of the study in de context of our institute. First, because the participants in this study had different mental disorders (psychotic,

bipolar, or depressive disorder), general measurement instruments were chosen for SMI, based on the MINI-plus and Routine Outcome Measurements [50].
At group level this was useful, but for the individual patient these outcomes are less specific. Second, this small study had no control group, with means that the results were interpreted with caution. Finally, in the study protocol it was guaranteed that during the NET at least biweekly professional support would be given. However mixed results showed that informal support was not always properly arranged. This meant that some close relatives were not given information about NET and its effects. As they did not always understand what was happening with the participant, they were less able to support.

7.4 Implications

Screening for PTSD

In clinical practice, trauma exposure and PTSD are still under-recognized in SMI patients, although it is known that 40% of SMI patients have comorbid PTSD, with a mean duration of 25 years [26, 51]. Possible factor for this, is probably that the main disorder in question (psychotic, bipolar, or major depressive disorder) attracts the most attention. In addition, patients are often reluctant to talk about their traumatic memories, as this can be stressful and can throw them off balance.
Periodic screening and detecting psychotrauma and comorbid PTSD is therefore of great importance because SMI patients are more at risk of current violence and have often experienced traumatic events in the past. Therefore, it is recommended that periodic screening for psychotrauma and PTSD for specific disorders (psychotic, bipolar and depressive disorders) should be included in all guidelines and care standards.
In clinical practice, it makes sense that team members are regularly trained in screening for trauma and PTSD. In this way PTSD can be detected earlier and treated appropriately. A possible instrument for screening trauma and PTSD is the short Trauma Screening Questionnaire (TSQ) is designed for survivors of all types of traumatic stress with a *Yes or No 10-item symptoms.* This instrument takes little time and is hardly burdensome [52]. With a positive score, it is recommended to administer the Life Events Checklist-5 (LEC-5) which consists of 17 possible traumatic events [53]. If there are traumatic events, the PTSD-checklist (PCL-5) with 20 items for the can be used. This checklist is based on the structured CAPS-5 interview [54]. For bipolar disorder the illness course, based on the Life Chart, is more effective. In addition, attention must be paid to possible dissociative and somatic disorders.

Diagnostic instruments

After a positive PTSD screening and with patient consent, a careful anamnesis is recommend and should including strengths and weaknesses, and possible extra co-morbid disorders. Significant others, such as close relatives and friends can be invited to provide important information. Subsequently, structured diagnostics of with CAPS-5 for PTSD [55] and if necessary for the present SMI with SCID-5 [56]. Fore specific disorders: PANSS in psychotic disorder [57], and the Hamilton Scale in depressive disorder [58]. For bipolar disorder the illness course, based on the Life Chart, is more effective. In addition, attention must be paid to possible dissociative and somatic disorders [40, 41, 59].

Implementation Narrative Exposure Therapy, shared decision making, and personal care

Because chronic PTSD affects the main disorder and overall functioning, NET and other trauma focused therapy should be more offered to SMI patients with comorbid PTSD. NET is specially indicated for patients with multiple trauma and together with the creation of the lifeline, provides exposure therapy in a chronological order. The testimonial character is very important for SMI patients, who often were not allowed to tell what had happened to them for years. During NET, participants were able to speak out, and they were confirmed in their multiple trauma life story by the NET therapist. This created a different and reconstructive perspective about the past and the present. Finally, the life story is an important tangible testimony.

SMI patients are often perceived as vulnerable in some ways, but they also show resilience, which is sometimes underestimated by therapists and caregivers. To take care of optimal conditions, the medical and psychological treatment of the primary disorder must be state of the art. Psychiatrists, Nurse Practitioners, and Clinical Psychologists, should work closely together with the involved supporting professionals and relatives. Nurses and social workers who have intensive contact with SMI patients and their closed relatives, usually are the first to observe changes in symptoms and care needs, during and after NET. They also provide the necessary support for patients to tolerate the NET. Nurses and social workers are not always sufficiently trained on psychotrauma, PTSD symptoms, and trauma-focused therapies such as NET. It is therefore important that they are adequately equipped to the principles of trauma informed care.

SMI patients who qualify for trauma focused therapy should receive oral and written information about the different possibilities such as: prolonged exposure, EMDR, brief eclectic psychotherapy for PTSD (BEPP), and NET. Based on this information, they can make a choice. After permission informed consent and prior to trauma focused therapy, the therapist invites the patient concerned, informal trusted caregivers, involved professionals to provide information and a shared decision [60]. This personalised care represents a relationship between people, professionals and the system. “It happens when we make the most of the expertise, capacity and potential of people, families and communities” [61]

Trauma informed care

Trauma Informed Care (TIC) promote five principles. First, physical and emotional safety is fostered through the physical environment, and interpersonal interactions. Second, trustworthiness occurs by maintaining boundaries and through transparency in policies and procedures for participants and staff. Third, choice is the extent to which participants and staff have control over their services and work experiences. Fourth, collaboration refers to the program’s power to share among staff and participants. Finally, empowerment, reflects the agency’s ability to acknowledge strengths and build skills (e.g., staff and client strengths in program planning, implementation, and evaluation are recognized) [62]. Mihelicova, Brown et al. 2018 [63] stated: “to inform trauma-responsive services, in individuals with SMI must be understood in a socio-ecological context. That is, the dynamic and transactional nature of personal characteristics, individual history, biological and psychological factors, the family systems, and society" [63]. This means that it is important that practitioners know the context of their patients, such as family, important friends and relatives, and their background. With this shared knowledge, practitioners can act more efficiently.

7.5 Conclusions and recommendations

The prevalence of interpersonal trauma exposure and PTSD is high in SMI patients, but is still insufficiently recognized in clinical practice. Given the seriousness and consequences of repeated trauma exposure and chronic PTSD, it is important that periodic screening is performed. After a positive screening test, a structured interview such as the CAPS-5 should be used for in-depth diagnosis. In SMI outpatients with a history of repeated interpersonal trauma exposure and comorbid PTSD, NET appeared efficacious, applicable, and was well tolerated. Repeated measures showed that after treatment 11 of 23 participants were in remission for PTSD, of which five were also in remission for major severe depressive disorder. Thus, in contrast to common practice, NET can be offered to SMI patients.

Mixed methods results showed substantial congruence between participants' perceptions and objective quantitative scores of PTSD, dissociative symptoms, and care needs. For participants, NET was an intensive therapy and it was important to them that they could tell about their traumatic life events and that they were recognized by the NET therapists. Remission of PTSD was associated to sufficient perceived professional and informal support. Patient support by FACT was continued with at least biweekly contact by Nurses en Social workers. This implies that successful NET depends on NET-therapists, working together with professional and informal supporters.

Trauma informed care in SMI should include all involved FACT-team members such as: Psychiatrists, Clinical Psychologists, Nurse Practitioners, and those who provide medical and psychical treatment.

Specialized psychiatric nurses and social workers play an important role in providing support. Patients and their close relatives should be involved as important partners. Finally, it is important that therapists and the FACT-team receive sufficient training and support.

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Addendum

SUMMARY

Introduction

Patients with Severe Mental Illness (Psychotic, Bipolar, and Major Depressive orders) often have experienced traumatic events during their lifetime. As a result comorbid posttraumatic stress disorder (PTSD) is often present. In clinical practice, trauma exposure and PTSD has not been recognized for a long time. This meant that no targeted diagnoses were made, let alone appropriate treatment. Therefore, this thesis aimed to study the prevalence of interpersonal trauma exposure and PTSD in SMI outpatients and the treatment of these traumas with Narrative Exposure Therapy (NET) in clinical practice.

Chapter 1

This chapter begins with a family story: “Stories from the past, shape the present”. It shows how a serious traumatic event leads to a new tragic event after more than forty years. These impressive stories have shaped me and inspired me to become a psychiatric nurse. They made me aware of the impact on humans of traumatic events and explained my search for the stories in people, especially in severe mentally ill patients.

My first job as a nurse consisted of caring for young patients with schizophrenia in a psychiatric hospital. These people perceived a lot of loss. At the time, little attention was paid to their experiences. My second job in a University Medical Centre, got me the opportunity to study nursing science. Loss and grief in schizophrenia became my first scientific topic.

Nine years later, I became leader of a Support & Psychosis team and provided nursing care to Severe Mentally Ill patients in GGNet. Although the team provided good care and medication, team consultations showed that patients often had a history of abuse and neglect, but implications for care and treatment were not further discussed. As a result, such information was not available in the patient’s records. Psychological interventions were not provided because the opinion was that SMI patients could not tolerate trauma focused treatment.

Thus, our team was confronted with SMI patients suffering from Posttraumatic Stress Disorder (PTSD), but effective treatment was not available. This triggered the questions how many of SMI patients suffered from trauma exposure, and what therapies would be available to PTSD. To answer these questions, we started a research project at GGNet in collaboration with Radboudumc.

Relevant concepts are further described in this chapter: psychotrauma, interpersonal trauma, PTSD, Complex PTSD, Dissociative Identity Disorder, Severe Mental Illness, and trauma focused therapy.

The first objective of this thesis was to study the relevance and clinical practice of treating PTSD in SMI patients. This was done by reviewing the prevalence of interpersonal traumatic experiences and PTSD in SMI patients and by a practice-based case study on the treatment of a patient with Complex PTSD using a three-phase treatment modality.

The second objective was to evaluate NET as a new emerging treatment for PTSD in SMI patients. To this end a mixed method study was designed, consisting of a quantitative strand and a mixed qualitative-quantitative strand. The thesis concludes with a general discussion.

Chapter 2

In clinical practice, trauma exposure and trauma related disorders in severe mental illness (SMI) have not been recognized for a long time. The objective of this study was to substantiate the prevalence of interpersonal trauma exposure and trauma-related disorders in people with SMI. Therefore, a

systematic review was conducted targeting child abuse, emotional abuse; emotional neglect; physical abuse; physical neglect; sexual abuse; physical and sexual assault. Trauma-related disorders consisted of PTSD, Complex PTSD, DESNOS and Dissociative Disorders. Thirty three studies were included, described and analysed in terms of primary diagnosis and instruments used to measure trauma exposure and trauma-related disorders. Population-weighted mean prevalence rates in severe mental illness were: physical abuse 47% (range 25-72%), sexual abuse 37% (range 24-49%) and PTSD 30% (range 20-47%).

Compared to men, women showed a higher prevalence of sexual abuse in schizophrenia spectrum disorder, bipolar disorder and mixed diagnosis groups labelled as having SMI. Prevalence rates of interpersonal trauma and trauma-related disorders were significantly higher in severe mental illness than in the general population. Emotional abuse and neglect, physical neglect, Complex PTSD and dissociative disorders have been scarcely examined in severe mental illness.

Chapter 3

This chapter describes and evaluates the therapeutic process of a single case from a holistic perspective on a female patient with co-morbid Complex PTSD and psychotic disorder. In this case trauma focused therapy (TFT) is often considered hard to endure. Therefore, Phase based treatment including (1) stabilization, (2) trauma focused therapy, and (3) integration of personality with recovery of connection, appeared to be the treatment of choice. The objective was to describe and evaluate the therapeutic process of this single case from a holistic perspective.

A 47-year-old woman was treated for severe Complex PTSD resulting from repeated sexual and physical abuse in early childhood and moderate psychotic symptoms stemming from Dandy Walker Syndrome with hydrocephalus. The patient was treated with medication. Stabilization consisted of intensive psychiatric nursing care in the home and stabilizing group treatment for Complex PTSD. After stabilization, the following symptoms showed improvement: self-regulation, self-esteem, assertiveness, avoidance of social activities, and negative cognitions. However, intrusions and arousal persisted, therefore prolonged imaginary exposure with writing assignments was provided. Then a final closing ritual was performed.

This phase-based approach proved effective: all symptoms of Complex PTSD were in full remission. Social integration and recovery were promoted by reduction of polypharmacy and the provision of social skills training and lifestyle training. This case showed that a phase-based treatment approach with collaborative care was effective for Complex PTSD with co-morbid psychotic disorder.

Chapter 4

In the Netherlands, most patients with SMI receive Flexible Assertive Community Treatment (FACT) provided by multidisciplinary community mental health teams. SMI patients with comorbid PTSD are sometimes offered evidence based trauma focused treatment.

Narrative Exposure Therapy (NET) has showed a large amount of evidence for the effectiveness in various vulnerable patient groups with repeated interpersonal trauma. Some FACT-teams provide NET for patients with comorbid PTSD in SMI patients, which is promising, but has not been specifically studied.

This chapter outlines a mixed methods convergent study design with a quantitative and qualitative strand, which was subsequently registered in the Netherlands National Trial Register (ID TR571). The primary aim was to evaluate NET in SMI patients (n=25) with comorbid PTSD associated with repeated interpersonal trauma, specifically whether: a) PTSD and dissociative symptoms changes and b) changes

occur in the present SMI symptoms, care needs, quality of life, global functioning, and care consumption. The second aim was to gain insight in patients' experiences with NET and to identify influencing factors on treatment results.
The quantitative study parameters were: existence and severity of PTSD, dissociative, and SMI symptoms; care needs; quality of life; global functioning; and care consumption. Outcomes were analysed using mixed models to estimate the difference in means between baseline and repeated follow up measurements. The qualitative study parameters were: experiences with NET and perceived factors for success or failure. Integration of quantitative and qualitative results aimed at interpreting how qualitative results enhance the understanding of quantitative outcomes. Integration of quantitative and qualitative results was focused on interpreting how qualitative results are interrelated and enhance the understanding of quantitative outcomes.

Chapter 5

This chapter describes that interpersonal trauma and PTSD in SMI patients negatively affect the course of illness. Narrative Exposure Therapy (NET) is effective in vulnerable patient groups, but its efficacy and applicability has not been studied in SMI outpatients. The aim was to evaluate efficacy and applicability of NET in SMI on changes in PTSD, dissociation, SMI symptoms, care needs, quality of life, global functioning, and care consumption.
The study had a single group pre-test-post-test repeated-measures design. Primary outcomes are PTSD and dissociation. The outcomes were assessed pre-treatment (T0), one month post-treatment (T1), and after seven months of follow-up (T2), using a structured interview for PTSD and screening for dissociation. Secondary outcomes followed SMI symptoms, care needs, quality of life, global functioning, care consumption; farmacotherapy, frequency and duration of clinical contact were extracted from patient records.
The majority of the 23 participants was female (82%). Mean age was 49.9 years (SD 9.8) and mean duration of PTSD was 24.1 years (SD 14.5). The score for PTSD severity decreased from a mean of 37.9 at T0 to 24.5 at T2 (-13.4, 95%CI -17.4 to -9.4). Dissociation, SMI symptoms, duration of contacts, and medication decreased, global functioning increased; quality of life, and perceived needs did not change. Eleven participants were in remission for PTSD at T2; five of them also for major depression. Conclusion was that NET appeared efficacious and applicable to SMI outpatients with PTSD and was well tolerated.

Chapter 6

This chapter describes the efficacy and experiences with NET in SMI patients with comorbid PTSD receiving FACT. SMI patients with repeated interpersonal trauma and PTSD have a negative course of illness. Traumas often remain untreated because of their vulnerability. Narrative Exposure Therapy (NET) is an effective trauma therapy. However, it is unknown whether NET is effective and tolerable in these EPA patients receiving community mental health care.
The objectives were 1) to gain insight into patient's experiences before, during and after NET concerning changes in PTSD, dissociative and SMI symptoms, care needs, quality of life, and global functioning; 2) to identify factors that influence diagnostic changes after NET as compared to patient's experiences. These insights will help to decide whether NET should be incorporated in usual care for these patients.

The mixed methods convergent design included a qualitative strand that used a Grounded Theory Approach with thematic analysis, combined with a quantitative strand with repeated measures. Qualitative data were collected three months after narrative exposure therapy (NET) using individual semi-structured in-depth interviews. The merged analysis compared quantitative and qualitative results for each participant by means of a joint matrix.

Twenty three outpatients (female 82%), mean age 49.9 years (SD 9.8) participated. Participants experienced NET as intensive, and most of them tolerated it well. Afterwards, eighteen participants perceived less symptoms. Mixed analysis showed substantial congruency between quantitative scores and participants' perception of PTSD, dissociative symptoms and care needs (Cohen's kappa>0.4). Remission of PTSD was associated to sufficient experienced support. Severe mentally ill outpatients experienced Narrative Exposure Therapy as intensive, and most of them tolerate it well. This therapy is clearly efficacious in this group.

Chapter 7

This final chapter includes the general discussion of the studies in this thesis. First, the findings are summarized and discussed in the context of clinical practice based on FACT in the Netherlands, and relevant literature.

Second, the methodological strengths and limitations are discussed.

Third, the main conclusions are: 1) The prevalence of trauma exposure and lifetime PTSD are very high in SMI, and in women twice as high as men, 2) Narrative Exposure therapy appeared efficacious and applicable to SMI patients with PTSD, 3) SMI patients experienced NET as intensive, and most of them tolerate it well.

Fourth, implications of these findings for clinical practice are: 1) SMI patients should be screened regularly for trauma exposure, 2) trauma focused therapy such as NET should be available to SMI patients, 3) with sufficient informal and professional support, 4) based on trauma informed care and shared decision, and 5) sufficient training should be offered to individual therapists as well as the FACT-team as a whole.

SAMENVATTING

Introductie

Patiënten met Ernstige Psychische Aandoeningen (EPA) - bestaand uit Psychotische, Bipolaire en Ernstige Depressieve Stoornissen – hebben vaak traumatische gebeurtenissen meegemaakt in hun leven. Als gevolg daarvan is er veelal ook een posttraumatische stressstoornis (PTSS) aanwezig. In de klinische praktijk wordt de blootstelling aan trauma's en de aanwezigheid van PTSS nog onvoldoende herkend. Dit betekent dat de diagnose PTSS dan niet wordt gesteld en als gevolg daarvan krijgen patiënten geen passende behandeling.

Het eerste doel van dit proefschrift is om vast te stellen wat de omvang is van blootstelling aan herhaald interpersoonlijk geweld en co-morbide PTSS bij patiënten met EPA en de behandeling van . PTSS deze trauma's met Narratieve Exposure Therapie (NET) in de klinische praktijk.

Hoofdstuk 1

Dit hoofdstuk begint met een familieverhaal: "Verhalen uit het verleden, vormen het heden". Het maakt duidelijk hoe ernstige traumatische gebeurtenissen leiden tot nieuwe tragische gebeurtenissen, soms na meer dan veertig jaar. Dergelijke indrukwekkende verhalen hebben mij gevormd en geïnspireerd om als verpleegkundige in de psychiatrie te gaan werken. Ze maakten mij bewust van de invloed op traumatische gebeurtenissen in het leven van mensen en hebben mijn interesse gewekt voor de levensverhalen, in het bijzonder van EPA patiënten.

Mijn eerste baan in de psychiatrie bestond uit verpleegkundige zorg voor jonge patiënten met Schizofrenie in een psychiatrische instelling. Deze mensen ervoeren grote verlieservaringen. In die tijd (1991) was er weinig aandacht voor hun ervaringen. Mijn volgende baan was in een Universitair Centrum. Daar kreeg ik de gelegenheid om Verplegingswetenschappen te studeren. Verlies en rouw bij Schizofrenie werd mijn eerste wetenschappelijk onderwerp.

Negen jaar later werd ik programmaleider van het team Support & Psychose bij GGNet. Daarnaast bood ik ook verpleegkundige en sociale zorg aan EPA patiënten. Het team zorgde goed voor deze kwetsbare patiënten, maar de behandeling bestond vooral uit farmacotherapie. Tijdens de bespreking van het behandelplan, viel het op dat patiënten vaak een geschiedenis hadden van misbruik en verwaarlozing, maar dat de gevolgen daarvan niet werden besproken. Bovendien werd deze informatie niet op een centrale plek in het patiëntdossier beschreven. In die tijd werden psychologische interventies nauwelijks ingezet omdat de algemene overtuiging was dat EPA patiënten cognitieve en traumagerichte therapie niet konden verdragen.

Zo werd ons team geconfronteerd met EPA patiënten die PTSS hadden, maar voor wie geen effectieve behandeling beschikbaar was. Dit riep de vraag op hoeveel EPA patiënten lijden aan gevolgen van blootstelling aan trauma en welke therapieën voor hen passend en beschikbaar zijn voor de behandeling van PTSS. Om deze vragen te beantwoorden zijn we gestart met een onderzoeksproject bij GGNet in samenwerking met Radboudumc.

In dit hoofdstuk worden belangrijke concepten beschreven: psychotrauma, interpersoonlijk trauma, PTSS, Complexe PTSS, dissociatieve identiteitsstoornis, ernstige psychische aandoeningen en traumagerichte therapie. Vervolgens voerden we een systematisch review uit om de prevalentie van interpersoonlijk trauma en PTSS bij EPA patiënten in kaart te brengen. Daarnaast wordt een casus beschreven uit de klinische praktijk, een zogenaamde drie-fasen behandeling bij een patiënte met Complexe PTSS en psychose.

Het tweede onderzoeksdoel was de evaluatie van NET, bij EPA patiënten met PTSS. Daarvoor is een gemengde methoden onderzoek opgezet, met een kwantitatieve arm en een gemengde kwalitatieve-kwantitatieve arm. Het proefschrift werd afgesloten met een algemene discussie.

Hoofdstuk 2

In de klinische praktijk is het voorkomen van traumatische gebeurtenissen en trauma-gerelateerde stoornissen bij EPA patiënten lange tijd niet herkend. De doelstelling van dit onderzoek was gericht op de prevalentie van blootstelling aan interpersoonlijk trauma en trauma-gerelateerde stoornissen bij EPA patiënten. Hiervoor werd een systematisch review uitgevoerd naar het vóórkomen van kindermishandeling; emotionele mishandeling; emotionele verwaarlozing; fysiek misbruik; fysieke verwaarlozing; seksueel misbruik; fysiek en seksueel geweld. Trauma-gerelateerde stoornissen waren PTSS, Complexe PTSS en dissociatieve stoornissen.

Drieëndertig studies werden geïncludeerd, beschreven en geanalyseerd in termen van de primaire diagnose en de meetinstrumenten gericht op trauma en trauma-gerelateerde stoornissen. De gemiddelde prevalentiecijfers bij EPA waren: lichamelijke mishandeling 47% (25-72%), seksueel misbruik 37% (24-49%) en PTSS 30% (20-47%). Vergeleken met mannen hadden vrouwen een hogere prevalentie van seksueel misbruik bij Schizofrenie Spectrum Stoornis, Bipolaire Depressieve stoornis en gemengde stoornissen gedefinieerd als EPA. De prevalentie van interpersoonlijk trauma en trauma-gerelateerde stoornissen was significant hoger bij ernstige psychische aandoeningen dan bij de algemene bevolking. Emotionele mishandeling en verwaarlozing, lichamelijke verwaarlozing, Complexe PTSS en dissociatieve stoornissen waren nauwelijks onderzocht bij EPA.

Hoofdstuk 3

Dit hoofdstuk beschrijft en evalueert het therapeutisch proces bij een casus vanuit een holistisch perspectief. De casus betrof een patiënte met een psychotische stoornis en co-morbide Complexe PTSS. In deze casus was de veronderstelling dat trauma gerichte therapie mogelijk niet te verdragen zijn. Daarom werd een fase-gerichte benadering voorgesteld, die bestond uit: (1) stabilisatie, (2) traumagerichte therapie en (3) integratie van de persoonlijkheid en herstel van verbinding met anderen.

Een 47-jarige vrouw werd behandeld voor ernstige Complexe PTSS als gevolg van herhaald seksueel en fysiek misbruik vanaf de vroege kindertijd. Zij had psychotische symptomen als gevolg van het Dandy Walker Syndroom waarbij tijdens de groei een waterhoofd ontstaat. Patiënte werd behandeld met antipsychotica en antidepressiva.

Stabilisatie bestond uit intensieve psychiatrische verpleegkundige zorg thuis en groepstherapie gericht op stabiliseren van de Complexe PTSS symptomen. Na stabilisatie verbeterde de volgende symptomen: zelfregulatie, eigenwaarde, assertiviteit, vermijding van sociale activiteiten en negatieve cognities. Echter, intrusies en prikkelbaarheid bleven hardnekkig, daarom werd langdurige imaginaire exposure met schrijfopdrachten aangeboden. De behandeling werd afgesloten met een afsluitend ritueel.

Deze fasegerichte benadering was effectief: alle symptomen van Complexe PTSS waren geheel in remissie. Sociale integratie en herstel werden bevorderd door het afbouwen van de polyfarmacie en het starten met sociale vaardigheidstraining en leefstijltraining. Deze casus liet zien dat een fasegerichte therapie, gesteund door gezamenlijke zorg effectief was bij Complexe PTSS met een co-morbide psychotische stoornis.

Hoofdstuk 4

In Nederland krijgen EPA patiënten meestal Flexible Assertive Community Treatment (FACT) dat uitgevoerd wordt door multidisciplinaire teams. EPA patiënten met co-morbide PTSS krijgen soms traumagerichte behandeling. Narratieve Exposure Therapie (NET) is een bewezen therapie, die over het algemeen effectief is bij verschillende kwetsbare patiëntengroepen, die herhaald interpersoonlijke trauma's hebben ondergaan. Sommige FACT-teams boden NET aan bij EPA patiënten met co-morbide PTSS, wat veelbelovend leek, maar niet specifiek was onderzocht.

Dit hoofdstuk beschrijft het ontwerp van een gemengde methoden convergent onderzoek met kwantitatieve en kwalitatieve componenten. De studies is geregistreerd in het Netherlands National Trial Register (ID TR571).

De eerste doelstelling is het evalueren van NET bij EPA patiënten (n=25) met co-morbide PTSS gerelateerd aan herhaald interpersoonlijk trauma. Hierbij is de vraag of a) PTSS en dissociatieve symptomen veranderen en b) of er veranderingen zijn in de aanwezige EPA symptomen, zorgbehoeften, kwaliteit van leven, algemeen functioneren en zorgconsumptie. De tweede doelstelling is inzicht krijgen in de ervaringen van patiënten met NET en het identificeren van factoren die de behandelresultaten beïnvloeden. De kwantitatieve parameters bestaan uit de aanwezigheid en ernst van de PTSS, dissociatieve symptomen en EPA indicatoren, bestaand uit zorgbehoeften, kwaliteit van leven, algemeen functioneren en zorgconsumptie. Uitkomsten worden geanalyseerd op basis van Mixed Models om het verschil in gemiddelden tussen nulmeting en vervolgmetingen te schatten. De kwalitatieve parameters zijn: ervaringen met NET en waargenomen factoren voor succes of falen. De integratie van kwantitatieve en kwalitatieve resultaten is gericht op de vraag hoe kwalitatieve bevindingen samenhangen met de kwantitatieve resultaten en hoe deze de interpretatie hiervan kunnen ondersteunen .

Hoofdstuk 5

Dit hoofdstuk laat zien dat interpersoonlijk trauma en PTSS het ziektebeloop bij EPA negatief beinvloeden. Narratieve Exposure Therapie (NET) is effectief bij diverse kwetsbare patiëntgroepen, maar de werkzaamheid en toepasbaarheid zijn niet onderzocht bij ambulante EPA patiënten. Het doel was daarom de werkzaamheid en toepasbaarheid van NET bij EPA te evalueren op basis van de veranderingen in PTSS, dissociatie, EPA-symptomen, zorgbehoeften, kwaliteit van leven, globaal functioneren en zorgconsumptie.

Het onderzoek bestond uit een pre-test-post-test ontwerp met herhaalde metingen in één groep. Primaire uitkomsten waren PTSS en dissociatie. Deze werden gemeten met een gestructureerd interview voor PTSS en dissociatieve screening voorafgaand aan de behandeling (T0), een maand na de behandeling (T1) en na zeven maanden follow-up (T2). Secundaire uitkomsten waren EPA symptomen, zorgbehoeften, kwaliteit van leven, algemeen functioneren, en zorgconsumptie bestaande uit farmacotherapie, frequentie en duur van contacten met de behandelaars.

De meerderheid van de 23 deelnemers was vrouw (82%). De gemiddelde leeftijd was 49.9 jaar (SD 9.8) and gemiddelde duur van PTSS was 24.1 jaar (SD 14.5). De gemiddelde score voor ernst van de PTSS verminderde van 37.9 vooraf (T0) naar 24.5 bij follow up T2 (-13.4, 95%CI -17.4 to -9.4). Dissociatie, EPA symptomen, de duur van contacten en gebruik van medicijnen verminderde, algemeen functioneren verbeterde, kwaliteit van leven en ervaren behoeften veranderden niet.

Bij follow up waren elf deelnemers in remissie voor PTSS, vijf van hen waren in remissie voor ernstige depressieve stoornis. De conclusie was dat NET werkzaam en toepasbaar en goed te verdragen is voor ambulante EPA patiënten met PTSS.

Hoofdstuk 6

Dit hoofdstuk beschrijft de werkzaamheid en de ervaringen met NET van EPA patiënten met co-morbide PTSS die naast steun ontvangen via FACT. EPA patiënten met herhaald interpersoonlijk trauma en PTSS hebben een ongunstig ziektebeloop. Trauma's worden vaak niet behandeld vanwege de kwetsbaarheid van EPA patiënten. Narratieve Exposure Therapie (NET) is een effectieve traumagerichte therapie. Het is echter niet bekend of NET effectief en draaglijk is voor EPA patiënten die FACT ontvangen.

De doelstellingen waren: 1) inzicht krijgen in de ervaringen van EPA patiënten vooraf, tijdens en na NET met betrekking tot veranderingen in de aanwezige PTSS, dissociatieve en EPA symptomen, zorgbehoeften, kwaliteit van leven en algemeen functioneren: 2) het identificeren van de factoren die leiden tot diagnostische veranderingen na NET, vergeleken met de ervaringen van de patiënten. Deze inzichten kunnen helpend zijn bij de beslissing om NET op te nemen in de gangbare zorg.

Het gemengde methoden onderzoek bestond voor het kwalitatieve deel uit de Gefundeerde Theorie Benadering en werd gecombineerd met herhaalde kwantitatieve metingen. De kwalitatieve data werden drie maanden na NET verzameld met individuele semi-gestructureerde diepte interviews. In de gemengde analyse werden deze gegevens vergeleken met behulp van een matrix.

Drie en twintig patiënten (82% vrouwen) met een gemiddelde leeftijd van 49 jaar (SD 9.8) namen deel aan het onderzoek. De deelnemers ervoeren NET als intensief en de meesten konden NET goed verdragen. Na afloop van NET ervoeren 18 deelnemers minder symptomen. De resultaten van de gemengde analyse lieten zien dat er sprake was van substantiële congruentie tussen kwantitatieve scores en kwalitatieve percepties van de deelnemers voor PTSS, dissociatieve symptomen en zorgbehoeften (Cohen's kappa>0.4). Remissie van PTSS was geassocieerd met ervaren passende en voldoende zorg. De conclusie is dat ambulante EPA patiënten NET ervoeren als intensief en de meesten van hen konden NET goed verdragen. Deze traumagerichte therapie is duidelijk geschikt voor deze patiënten.

Hoofdstuk 7

Dit laatste hoofdstuk bevat de algehele discussie van de studies in dit proefschrift. Ten eerste worden de bevindingen opgesomd en besproken in de context van de klinische praktijk en gebaseerd op FACT in Nederland en relevante literatuur.

Ten tweede worden de methodologische sterke punten en de beperkingen besproken.

Ten derde, de algemene conclusies zijn: 1) de prevalentie van blootstelling aan trauma en PTSS gedurende de levensloop is heel hoog bij EPA patiënten en bij vrouwen twee keer zoveel dan bij mannen. 2) Narratieve Exposure Therapie bleek effectief en toepasbaar bij ambulante EPA patiënten met PTSS, 3) EPA patiënten ervoeren NET als intensief en de meesten van verdroegen het goed.

Ten vierde, implicaties van deze bevindingen voor de klinische praktijk zijn: 1) EPA patiënten moeten regelmatig gescreend worden op eventuele blootstelling aan traumatische gebeurtenissen, 2) Trauma Gerichte Therapie zoals NET, moet beschikbaar zijn voor EPA patiënten, 3) met voldoende informele en professionele zorg, 4) gebaseerd op trauma geïnformeerde zorg en gedeelde beslissingen en 5) voldoende training moet worden aangeboden zowel aan individuele therapeuten als het gehele FACT-team.

About the author

Maria Mauritz was born in Huizen, the Netherlands (August 9, 1965). She followed her vocational training at the Leidse Onderwijs Instellingen (1982-1984), she was assistant in a General Practice (Weesp, 1984-1987). Subsequently, she followed the training as a bachelor in Nursing at the Vijverberg (Ede, 1987-1991). As a nurse, she took care of schizophrenia, bipolar and severe depressive patients in the psychiatric hospital at Wolfheze. After two years, she moved to the clinical unit for eating and compulsive disorders at the UMC Utrecht (1993-2001). In 1994 she started her Master in Nursing Science in Utrecht and graduated cum laude (1999). She received the *Talma Eykman award* on her Master thesis: "Loss and grief in patients with schizophrenia. On living in another world" (2000).

Because of her interest in professional training of nurses, she became the manager of Nursing at the Christian University of Applied Sciences (CHE) in Ede (2001-2004). After three years, she continued her career in psychiatric care as a program leader and practitioner in severe mental illness at GGNet, Zevenaar. She was involved in the Multidisciplinary Guideline Personality Disorders, Nursing Care (2005-2008) and was further trained in Marital and Family Therapy at RINO Utrecht/Amsterdam (2008-2011). Subsequently, she completed her training as a Master of Advanced Nursing Practice (MANP) at the Hogeschool Utrecht and graduated cum laude (2013).

In 2012, Maria initiated an expert group on Complex Trauma in GGNet and she was subsequently asked to lead the "Poli Complex Trauma'', a mental health care unit in Doetinchem which specialized in diagnosis and treatment of patients with childhood trauma, (complex) Posttraumatic Stress Disorder (PTSD) and dissociative disorders (2013-2017). Since 2018, she works mainly with severe mentally ill patients with comorbid PTSD at GGNet in Zevenaar. Maria received professional training in structured diagnostic interviews such as CAPS-5 and SCID-D. Training in trauma focused therapies included prolonged exposure, Narrative Exposure Therapy (NET) (2012), Eye Movement Desensitization and Reprocessing (EMDR) (2014), and Brief Eclectic Psychotherapy for PTSD (BEPP) (2014). She was registered for Narrative Exposure Therapy (NET) in 2016. As a Nurse Practitioner, she contributed to the development of t*he national care standard for dissociative disorders in nurses and Nurse Practitioners with diagnoses and interventions* (2020).

Because of her scientific interest and experiences with psychiatric patients, she started her research on trauma and PTSD in patients with severe mental illness in 2010. Based on the paper in Chapter 2 of this thesis, she was nominated for the Anna Reynvaan science award (2014). Recently, she received *the publication award* of V&VN VS (2022) based on the paper in Chapter 5.
To advance professional nurses and other mental health practitioners within and outside the GGNet organization, she provided courses on severe mental illness, psycho-trauma, PTSD, dissociative disorders, structured diagnostic interviewing and NET, to various professional groups such as nurses, social workers, nurse practitioners, psychologists, and psychiatrists.

Over de auteur

Maria Mauritz werd geboren op 9 augustus 1965 in Huizen. Na de middelbare school volgde ze opleiding tot doktersassistente bij de Leidse Onderwijs Instellingen (1982-1984) en daarna werd zij dokters-assistente bij een huisarts in Weesp (1984-1987). Vervolgens heeft zij de HBO-Verpleegkunde gevolgd aan de Vijverberg in Ede (1987-1991). Als verpleegkundige bood ze zorg bij patiënten met schizofrenie, bipolaire en ernstige depressieve stoornissen in Psychiatrisch Ziekenhuis Wolfheze. Na twee jaar ging ze werken op de klinische afdeling voor eet- en dwangstoornissen in het UMC Utrecht (1993-2001). In 1994 begon zij met de opleiding Verplegingswetenschappen in Utrecht en in 1999 studeerde ze cum laude af. Ze ontving de *Talma Eykman Prijs* voor haar scriptie: "Als je er niet meer bij hoort: over leven in een andere wereld. Een onderzoek na verlieservaringen en uitingen van rouw bij patiënten met schizofrenie" (2000).
Vanwege haar interesse in de beroepsopleiding van verpleegkundigen werd zij manager Verpleegkunde aan de Christelijke Hogeschool (CHE) in Ede (2001-2004). Na drie jaar vervolgde zij haar loopbaan in de geestelijke gezondheidszorg als programmaleider en behandelaar voor ernstige psychische aandoeningen bij GGNet, Zevenaar. Ze was betrokken bij de Multidisciplinaire Richtlijn Persoonlijkheidsstoornissen (2005-2008) en volgde de opleiding relatie- en gezinstherapie bij RINO Utrecht/Amsterdam (2008-2011). Vervolgens heeft zij haar opleiding tot Master of Advanced Nursing Practice (MANP) aan de Hogeschool Utrecht cum laude afgerond (2013).

In 2012 startte Maria de expertkring Complex Trauma in GGNet. Kort daarna werd ze gevraagd om programmaleider te worden bij de "Poli Complex Trauma'', die gespecialiseerd is in diagnostiek en behandeling van patiënten met een geschiedenis van herhaald trauma in de kindertijd, (Complexe) Posttraumatische Stressstoornis (PTSS) en dissociatieve stoornissen (2013-2017).
Vanaf 2018 werkt ze voornamelijk met patiënten met ernstige psychische aandoeningen (EPA) en co-morbide PTSS. Ze is geschoold in gestructureerde diagnostiek zoals de CAPS-5 en de SCID-D. Daarnaast is zij getraind in traumagerichte therapieën, waaronder Prolonged Exposure, Narratieve Exposure Therapie (NET) (2012), Eye Movement Desensitization and Reprocessing (EMDR, 2014) en Beknopte Eclectische Psychotherapie voor PTSS (BEPP, 2014). In 2016 is ze geregistreerd voor Narratieve Exposure Therapie (NET). Als Verpleegkundig Specialist GGZ, heeft ze bijgedragen aan de ontwikkeling van de landelijke zorgstandaard dissociatieve stoornissen, gericht op verpleegkundige diagnostiek en interventies voor verpleegkundigen en Verpleegkundig Specialisten GGZ (2020).
Vanwege haar wetenschappelijke interesse en de ervaringen met EPA patiënten, begon zij in 2010 haar onderzoek naar trauma en PTSS bij EPA patiënten. In 2014 werd ze genomineerd voor de Anna Reynvaan prijs, gebaseerd op het artikel in hoofdstuk 2. Onlangs kreeg zij de *Publicatie Prijs van V&VN Verpleegkundig Specialisten (VS) (2022) op basis van het artikel in hoofdstuk 5.*
Daarnaast geeft ze regelmatig onderwijs aan verschillende beroepsgroepen in de GGZ zoals verpleegkundigen, agogen, psychologen en psychiaters om hen toe te rusten, binnen en buiten GGNet. Haar thema's zijn onder meer EPA, psychotrauma, PTSS, dissociatieve stoornissen, gestructureerd diagnostisch interviewen en traumagerichte therapieën.

LIST OF PUBLICATIONS

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8. Mauritz, M.W. & van Meijel, B., (2006). *Verlies en rouw bij patiënten met schizofrenie. Over leven in een andere wereld.* Nederlands-Vlaams Wetenschappelijk Tijdschrift voor Verpleegkunde, 13, 128-138

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RESEARCH DATA MANAGEMENT

Ethics statement

This thesis includes research on human subjects and has been conducted according to the principles of the Declaration of Helsinki, amended by the 59th WMA General Assembly, Seoul, October 2008.
The ethical approval for conducting the mixed methods study ''NET for PTSD in SMI patients'' was provided by the Committee on Research Involving Human Subjects, Arnhem-Nijmegen, Nijmegen (number 1843-2015). The study protocol was registered in The Netherlands National Trial Register (NTR) with number NTR5714. The study was conducted from 2016 to 2018 and the authors assert that the conduct of the research complied with the above-mentioned protocol. The study started in April 2016 and ended in January 2019.

Consent and data management

All participants declared informed consent to participate in this research. No incentives were provided to participants. For the prevalence study in (Chapter 2) and the study protocol (chapter 4) no ethical approval was obliged. The raw and analyzed data used in Chapter 2 are stored on the secured server of Radboud University Medical Center, Radboud Institute for Health Sciences, IQ healthcare, Nijmegen.
The person involved in the case study (Chapter 3) has given informed consent for the use of descriptive data and the electronic record. These data are stored at GGNet Center for Mental Health Care, Warnsveld, Netherlands (GGNet).
For the quantitative data (Chapter 5) informed consent was given before the collection of raw data. Medical quantitative data were collected with paper-recorded structured interviews and electronic record data. The analysis with SPSS was done at GGNet (chapter 5). These data are secured and stored at GGNet. The qualitative interviews and analysis (Atlas ti) are also stored at GGNet (Chapter 6).

These data will be saved for 15 years after termination of the respective studies.

DANKWOORD

It takes a village to raise a Thesis

De aanzet voor dit proefschrift begon op een zeer warme dag in Kroatië, toen onze tweejarige zijn middagslaapje hield en wij de tijd hadden om te filosoferen. Ik voelde me al langere tijd niet tevreden over de behandeling van patiënten met ernstige psychische aandoeningen (EPA). Vaak bleek dat zij een geschiedenis hadden van herhaald trauma en waarschijnlijk ook PTSS. In 2010 was er nog relatief weinig kennis over trauma en PTSS bij deze patiënten. **Pieter,** jij steunde mij in mijn wens om deze onvrede en leemte om te zetten in wetenschappelijk onderzoek bij deze patiënten.

Wetenschappelijk ben ik gevormd in Utrecht. **Mieke Grypdonck** heeft mij geinspireerd en grondig geschoold in de verplegingswetenschappen. **Berno van Meijel,** van jou heb ik in mijn Utrechtse tijd geleerd wetenschappelijke artikelen te schrijven, getuige onze gezamenlijke publicaties. Je zag mijn drive en potentie, en als we elkaar weer eens ontmoetten op een congres, dan zei je steevast: “wanneer ga je nou promoveren?” Nu is het dan zover!

Kort na de vakantie in Kroatië ging ik naar **Peter Goossens** bij Dimence. Ik had zijn proefschrift gezien en was benieuwd. Zo trok ik de stoute schoenen aan en maakte een afspraak. Peter, jij ontving mij hartelijk in Deventer en onze eerste kennismaking was zeer geanimeerd. Ik weet nog dat jij mij gegoogeld had en dat het resultaat ermee door kon. Na twaalf jaar zijn onze gesprekken nog steeds geanimeerd. Ik ben je heel dankbaar voor jouw waardevolle ideeën. Het was jouw voorstel een review te doen om in kaart te brengen hoe vaak trauma en PTSS voorkomt bij EPA patiënten. De uitkomsten waren indrukwekkend en lieten zien dat dit veel vaker voorkwam dan gedacht. Nu is dit artikel al 240 keer geciteerd! Enkele jaren later stelde jij voor om mijn onderzoekvragen met een Mixed Methods Design aan te pakken. Kwantitatieve en kwalitatieve data bij elkaar brengen bleek heel intensief, maar ook inspirerend en de resultaten gaven veel inzicht. Toen ik een focus interview voorstelde met de NET-therapeuten in het onderzoek, wilde jij wel de moderator zijn. Ik was onder de druk hoe jij dat proces leidde. Je hebt daarnaast gezorgd dat ik genomineerd werd voor de Anna Reynvaan Wetenschapsprijs in 2014 en wat was dat een stralende dag. Recent maakte je mij attent op de eerste Publicatie Prijs voor verpleegkundig specialisten (V&VN VS). Ik ben heel blij dat ik deze prijs heb gekregen! Je bent voor mij altijd bemoedigend en je kritiek is opbouwend. We delen veel ervaringen, zo zijn we in Utrecht door de zelfde hoogleraar gevormd: Uit Vlaanderen kwam en komt nog steeds veel goeds! Wij zijn allebei Verpleegkundig Specialist GGZ en wat is dat een mooi vak. We behandelen kwetsbare patiënten en zorgen daarnaast voor goede kennisoverdracht. Jij gaf mij ook de gelegenheid om in Gent onderwijs te geven bij **Karel Desmet**. Nu kwam Nederland naar Vlaanderen. Het was een goede ervaring. Tenslotte, we houden van taal en kwalitatief onderzoek. Graag wil ik met jou de rijke kwalitatieve data die er nog zijn, verder analyseren. Dat is dan “nadien”!

Theo van Achterberg, bij de aanvang van het onderzoek was jij mijn promotor en dat betekende dat ik in Nijmegen aan de slag kon bij het Radboudumc. Jij zorgde voor een aanstelling als promovenda bij IQ Healthcare. Ik herinner me nog goed hoe we in Utrecht onze gesprekken hielden met Peter en Nel. Dat was soms zoekend, maar vaak ook inspirerend. In mijn ogen stelde jij je bescheiden op en je was een goede luisteraar. De eerste twee studies heb jij begeleid waarbij het duidelijk was dat je naast verplegingswetenschapper ook epidemioloog bent. Dank voor jouw inzet voor mijn onderzoek. Jij vertrok naar de Katholieke Universiteit Leuven en het afscheidsfeest van jou met ieder in witte kleding herinner ik me nog goed. Je huidige titel *Professor of Quality of Care* past helemaal bij jou. **Nel Draijer,**

voor mij ben jij de Grande Dame in Nederland als het gaat om de kennis van verwaarlozing, mishandeling, seksueel misbruik in de kindertijd en de schrijnende effecten daarvan. Je leerde mij de mores in “trauma land”, hoe belangrijk het is om de juiste begrippen te gebruiken. Je overziet het speelveld en je hebt daarnaast veel kennis van complexe PTSS en dissociatieve stoornissen. Jouw bijdrage als expert was essentieel voor de prevalentie studie. Na een van onze overleggen vertelde ik over een patiënte, jij was direct geïnteresseerd en raadde mij aan deze ervaring te verwerken tot een case studie, waar van acte in dit proefschrift. **Lisette Schoonhoven,** ooit waren we studiegenoten en later was ik bij jouw promotiefeest in Amsterdam. Nadat Theo vertrok, werd jij mijn interim copromotor. Dank voor jouw inzet destijds. Ik vind het bijzonder, dat je na Southampton nu in Utrecht hoogleraar bent. Terug naar je roots. **Maria Nijhuis-van der Sanden (Ria)**, jij nam het stokje tijdelijk over van Theo als promotor. Ik heb jou ervaren als een doorgewinterd hoogleraar, praktisch, snel en zeer besluitvaardig. Dat past goed bij fysiotherapie. Wij hadden graag langer willen samenwerken, maar jouw pensioengerechtigde leeftijd stond dat niet toe. Dank voor jouw adviezen, de bemoediging en de gezellige praatjes op de gang. **Betsie van Gaal**, toen ik jou beter leerde kennen, viel mij op hoe snel je liep - naar het restaurant bijvoorbeeld - je leek mij slagvaardig en nuchter, echt een A-verpleegkundige dacht ik. Die eigenschappen meen ik ook te zien in het omgaan met jouw promovendi en studenten. Je bent altijd stipt op tijd, komt snel “to the point” en ziet scherp wat niet klopt. Je geeft desgevraagd en soms ongevraagd goed advies, maar je gaat niet onnodig zorgen. Onze samenwerking begon met het ontwikkelen van het onderzoeksprotocol en wat was dat een pittige klus. Ik heb in die tijd veel van jou geleerd. Na goedkeuring door de medisch-ethische toetsingscommissie werd ook het protocol-artikel snel gepubliceerd. Deze stevige basis hielp enorm bij de uitvoering van het onderzoek en de beschrijving van de resultaten. Jij bent zowel in kwantitatief als kwalitatief onderzoek zeer bekwaam. De begeleiding van het Mixed Methods Design was daarom bij jou in goede handen. Ik heb je leren kennen als een harde werker en als ik om feedback vroeg kreeg ik snel antwoord, vaak kwam er op zondagavond nog een bericht met zinnige opmerkingen. Ik dank jou voor al deze jaren waarbij jij mij bemoedigde en bij “nood” beschikbaar was. **Ruud Jongedijk,** in 2012 zag ik een bericht over de opleiding Narratieve Exposure Therapie (NET). Ik was direct geïnteresseerd omdat het om herhaald trauma ging en de omdat deze therapie chronologisch werd uitgevoerd aan de hand van de levenslijn. Het getuigeniskarakter vond en vind ik nog steeds inspirerend. Jouw onderwijs en workshops waren boeiend en het leggen van mijn eigen levenslijn samen met andere studenten gaf mij veel inzicht. De eerste NET behandelingen die ik uitvoerde bij EPA patiënten hadden goed effect. Het was intensief, maar patiënten konden het verdragen. Zo kwam het dat ik deze behandeling wilde onderzoeken bij EPA patiënten. Samen beschreven we het behandelprotocol in 2016. Jij was en bent altijd enthousiast over dit onderzoek. Je deed ook actief mee als observator bij het focus interview van de NET therapeuten. Van je inhoudelijke deskundigheid heb ik heel veel geleerd. Jij bent in mijn ogen een alleskunner. Naast je rol als psychiater was je lang directeur van ARQ/Centrum ’45. Je verzorgt nog steeds trainingen. Je schrijft over NET, nam deel aan het Handboek Posttraumatische stressstoornissen en de DSM-5. Tussendoor doe je wetenschappelijk onderzoek! Dank voor jouw adviezen en zinvolle feedback. Last but not least, **Hester Vermeulen**, jij kwam in 2017 als hoogleraar bij het Radboud Instituut voor Gezondheidswetenschappen IQ Healthcare. Jouw thema’s zijn de verbetering van de gezondheidszorg door middel van wetenschap en verpleegkundig leiderschap. Daarnaast ben je betrokken bij de Hogeschool van Arnhem en Nijmegen. Jouw achtergrond is de algemene gezondheidszorg (AGZ). De Geestelijke Gezondheidszorg (GGZ) was letterlijk en figuurlijk ver van het bed. Aanvankelijk leken we soms een andere taal te spreken, maar dat veranderde en was verrijkend voor mij. Daarnaast zijn we van dezelfde generatie en allebei kinderen uit Noord-Holland. Wij komen

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Kees Lemke en **Frans Kamsteeg**, jullie gaven mij binnen GGNet de ruimte om praktijkgericht wetenschappelijk onderzoek te doen en daarover te reflecteren. Jullie stimuleerden het organiseren van twee symposia binnen GGNet. Dank voor de mogelijkheden die jullie mij hebben geboden! **Yolanda Huisman**, wat was het prettig met jou samen te werken bij de Poli Complex Trauma, waarbij jij mij steunde in de rol van programmaleider. Je maakte lange ritten en gaf daar niet om. Daarnaast ken ik je als altijd opgewekt en mensgericht. Dankjewel! **Nanda Los**, als ik je nodig heb dan ben jij er. Je hebt een "grote klus" te doen en dat is pittig, want veranderen is nooit gemakkelijk. Tegelijkertijd blijf je voeling houden met ons als medewerkers op een transparante manier. Dank daarvoor! **Wanda Pol**, als onderzoeksassistent heb jij 66 gestructureerde interviews gehouden. Zo kwam je bij patiënten in alle regio's van GGNet. Je hebt de resultaten secuur ingevoerd in SPSS. Hartelijk dank! **Henk Seinen, Marloes de Graaf, Mireille Witteveen, Fabian Schug en Evelien Veldboom**, jullie zijn de ruggengraat van dit onderzoek. In 2015 hebben **Ruud Jongedijk, Patricia Strijk** en **Gerdie Eiting** jullie samen met 15 andere therapeuten geschoold in Narratieve Exposure Therapie en de bijbehorende groepssupervisie. Bij elkaar hebben jullie 22 patiënten behandeld. In de interviews die ik hield na de NET, hoorde ik hoe jullie omgingen met kwetsbare patiënten. Eén van jullie gaf een gitaar aan iemand die dit niet kon betalen. Een andere patiënt was verrast dat de therapeute na vier jaar haar hobby nog kende. Veel patiënten waren blij dat ze de tijd kregen om hun verhaal te doen over nare gebeurtenissen in hun leven. Ze mochten verdrietig zijn en werden gehoord. Daarbij was duidelijk dat de ondersteuning van kundige begeleiders van groot belang was. Als representant van jullie, bekleedt **Evelien** vandaag de rol van paranimf.

En dan de **deelnemers in dit onderzoek**, uiteindelijk gaat om het jullie. Het begon met de toestemming om persoonlijke gegevens te gebruiken voor het onderzoek. Jullie durfden een trauma behandeling aan te gaan met narratieve exposure therapie. Het vertrouwen in de behandelaars en de hoop dat het beter kon worden motiveerden jullie. Wat was het waardevol dat jullie persoonlijke ervaringen gedeeld hebben. Ik heb veel van jullie geleerd. Dankzij dit onderzoek kunnen andere behandelaars NET aanbieden bij mensen als jullie die veel nare gebeurtenissen hebben meegemaakt.

Dichter bij huis…

Mijn ouders - Willem Mauritz en Annie Klein - hadden bij mijn geboorte, hun eerste kindje, vast niet gedacht dat er nog elf kinderen zouden volgen. Uiteindelijk werden het zes dochters en zes zonen. Ze zijn beiden overleden en dat blijft een groot gemis, maar wat een rijke erfenis hebben we meegekregen. Naast een muzikale vader, organist en een goede accountant, was onze moeder getalenteerd in naaien, tekenen en schilderen. Ze was zorgzaam en begreep wat anderen bezig hield. Ze hield van kinderen en kon goed met hen knutselen en spelen. Daarnaast heb ik heel veel geleerd van mijn Oma Zwaantje Gooier en Opa Gerrit Klein. Ze namen de tijd voor mij en vertelden mooie verhalen uit het verleden. Niet voor niets begint dit proefschrift met het verhaal van mijn Opa.

In ons gezin komen de talenten van onze ouders naar boven. **Zwany**, jij hebt veel artistieke gaven: je bent van beroep coupeuse en daarnaast kun je tekenen, schilderen en musiceren. **Gert**, lang geleden deed je administratie voor een groot bedrijf, je was een tijdje kok en uiteindelijk vond jij je roeping als

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Nu werk jij weer in het onderwijs en ik in de zorg. Altijd genoeg gespreksstof! Lieve **Rita**, het is alweer 18 jaar geleden, dat ik jouw collega programmaleider werd. Jij maakte me wegwijs in het Juvenaat in GGNet Zevenaar. Ik bewonderde hoe jij met patiënten omging, liefdevol, nuchter en begrensd. Daar leerde ik van. Nu geniet je jouw pensioen en heb je alle tijd voor jouw dierbaren, de vele interesses en mooie reizen. Lieve **Henriëtte**, in Doetinchem werkten we bij poli complex trauma, we waren daar de eerste Verpleegkundig Specialisten die traumagericht werkten, en dat deed ons beiden goed. We werken nu op andere plekken, maar complex trauma en PTSS blijven belangrijke topics voor ons. **Gerlies**, wat heerlijk om een vriendin op loopafstand te hebben. Dank voor jouw steun, de goede gesprekken, de gedeelde verpleegkundige ervaringen en de lekkere maaltijden. Lieve **Sofie**, je bent mijn schoonzus, maar nog veel meer een goede vriendin. Altijd opgewekt, mooi gekleed en een groot hart voor anderen. Wat is het heerlijk om een oudere zus te hebben en tegelijkertijd het 'oudste- zijn' te kunnen delen. Dank ook aan jouw dochter **Judith** die mij heeft geholpen om de 'puntjes op de Engelse i' te zetten, vooral in de niet-wetenschappelijke passages in dit proefschrift. En niet te vergeten dank voor alle lieve mannen en vrouwen die horen bij mijn vriendinnen. Al kwamen zij wat later in mijn leven, ze zijn mij allemaal heel dierbaar!

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Tenslotte, **Pieter**, jij hebt bijna alle academische rollen gehad: student, master, ingenieur, promovendus, doctor, hoogleraar en voorzitter van promoties. Eén miste er nog: wat fijn dat jij vandaag met **Evelien** mijn paranimf wilt zijn!

EPILOGUE

Raak de wonden aan

We dragen veel wonden met ons mee waarvan het nodig is om deze bloot te leggen, zodat ze kunnen genezen (en zo dat wij daardoor kunnen meehelpen de wonden van anderen te genezen). Daar horen zowel pijnlijke, maar ook de vergeten of nooit ontdekte en toegegeven trauma's bij, evenals onze teleurstellingen en beschadigingen 'door het lot'. Het gaat om de wonden die anderen *ons* hebben toegebracht, maar ook de wonden die wij *(*misschien wel *bona fide*) *anderen* hebben toegebracht en die (ook als wij ons daarvan vaak niet bewust waren) ons vaak meer beschadigen dan de wonden die wij door anderen opliepen.

Tomáš Halík.
Raak de wonden aan. Over niet zien en toch geloven. Kok Boekencentrum Utrecht, 2018.

Touch the wounds

We all carry with us many wounds that need to be exposed so that they can heal (and so that we can help to heal the wounds of others). This includes painful, but also forgotten or never discovered and admitted trauma's, as well as our disappointments and bruises 'by fate'. These are the wounds that others have inflicted on us, but also the wounds that we (perhaps *bona fide*) have inflicted to others and which (even if we were not aware of it) often do more damage to ourselves than the wounds we received from others.

Tomáš Halík
Touch the wounds. Translated to Dutch by the author of this thesis.

Tomáš Halík (1948) is a Czech Catholic priest, psychotherapist, philosopher, and theologian. He is a professor of Sociology, pastor in Prague and president of the Czech Christian Academy.

PhD portfolio of Maria Mauritz

Department: Scientific Centre for Quality of Health Radboud, IQ healthcare
PhD period: 01-04-2010 – 22-10-2022
Promotor(s): Prof. Dr. H. Vermeulen & Prof. Dr. P.J.J. Goossens
Copromotor(s): Dr. H.G.I. van Gaal

Training activities	Hours
Courses	
- Master Advanced Nursing Practice, Hogeschool Utrecht (2012-2013)	120 ECTS
- Instruction literature search strategy by librarian, Nijmegen (2011)	2
- Workshop Reference manager, Nijmegen (2011)	8
- Symposium Rho Chi V&VN WiP: 'Op weg naar excellent verplegen: je rolmodel leren' (2014)	8
- Qualitative Research Methods in Health Care, Radboudumc (2016)	24
- Cursus Biometrics, Health Academy Radboudumc (2019)	56
Seminars	
- PhD-education IQ Healthcare (2012)	6
- PhD-education IQ Healthcare (2013)	3
- PhD-education IQ Healthcare (2014)	3
- PhD-education IQ Healthcare (2016)	3
- PhD-education IQ Healthcare (2017)	6
- IQ Healthcare (*oral presentation*): Trauma en PTSS bij patiënten met EPA (2018)	16
- IQ Healthcare (*oral presentation*): Mixed methods integral analysis: merging results, mixed feelings? (Met Silvio van den Heuvel) (2018)	16
Conferences	
- *Workshop* Effectieve verpleegkundige zorg voor patiënten met ernstige psychiatrische aandoeningen (EPA) en complexe trauma gerelateerde stoornissen. Een uitdaging voor FACT-Teams?! FACT-congres: netwerken werkt, FACT & GGNet Maarssen, (2013)	16
- *Oral Presentation* Patiënten met ernstige psychiatrische aandoeningen en complexe traumatisering: who cares? Als zwijgen over het onzegbare geen goud is…hoe dan het gesprek aan te gaan? Steiger Congres/ GGZ verpleegkundigen congres, Arnhem (2013)	16
- *Workshop* Verpleegkundige zorg voor patiënten met ernstige psychiatrische aandoeningen (EPA) en een geschiedenis van vroegkinderlijke Chronische Traumatisering. Landelijk congres "Vroegkinderlijke Chronische Traumatisering: Diagnostiek en Behandeling van psychische gevolgen in de volwassenheid", Veldhoven (2013)	24
- *Workshop* Verpleegkundige zorg aan mensen met EPA en complex trauma, Lustrum MANP en verzekeraars: partners ineffectieve en efficiënte zorg, Doorn (2014)	16
- *Oral presentation* Anna Reynvaan Wetenschapsprijs: Prevalence of interpersonal trauma exposure and trauma related disorders in severe mental illness, review, Amsterdam (2014)	16
- *Poster* Prevalence of interpersonal trauma exposure and trauma-related disorders in severe mental illness (2014)	8
- *Poster* Phase-based treatment of a complex severe mentally ill (SMI) case involving Complex Posttraumatic Stress Disorder and psychosis related to Dandy Walker Syndrome (2014)	8
- *Workshop* Verpleegkundige zorg aan mensen met EPA en complex trauma, Lustrum MANP Verpleegkundig Specialisten en verzekeraars, Doorn (2014)	16
- *Workshop* Prevalentie van interpersoonlijk geweld en trauma gerelateerde stoornissen bij ernstige psychiatrische stoornissen: een review, NtVP & Sympopna, "Kansen en obstakels in de Psychotraumahulpverlening", Ede (2014)	24
- *Oral presentation* Narratieve Exposure Therapie voor PTSS na herhaald trauma bij patiënten met EPA: een gemengde methoden onderzoek, GGNet, Doetinchem (2016)	8
- *Oral presentation* research paper Phase-based treatment of a complex severe mentally ill case involving Complex PTSD and psychosis related to Dandy Walker Syndrome, European Society Trauma Dissociation, Amsterdam (2016)	36

- *Organisatie Symposium* GGNet Zutphen & Workshop Narratieve Exposure Therapie Therapie (NET) voor PTSS na herhaald trauma bij patiënten met EPA: Een gemengde methoden onderzoek, Zutphen (2017)	36
- *Workshop* Narratieve Exposure Therapie (NET) bij ernstige psychische aandoeningen en co-morbide PTSS: Verbetering van de kwaliteit van leven door gerichte behandeling en onderzoek naar effect en betekenis, CELEVT, Amersfoort (2017)	24
- *Oral presentation* Trauma en PTSS bij ernstige psychische aandoeningen diagnostiek en behandeling: van zorgprogramma naar implementatie, Zevenaar (2018)	16
- *Oral presentation* Narrative Exposure Therapy for PTSD in patients with Severe Mental Illness: a mixed methods design, Evidence based clinical practice/scientific research, 10th ICN NP/APN Conference, Rotterdam (2018)	36
- *Oral presentation* NET for SMI patients with PTSD, On getting a different life. Shaping the future of community mental health care, Verona (2019)	36
- *Oral presentation* Narratieve Exposure Therapie voor PTSS bij psychose: Ervaringen uit de praktijk en voorlopige resultaten van onderzoek, UMC Utrecht (2019)	16
- *Oral presentation* Narratieve Exposure Therapie voor co-morbide PTSS bij patiënten met Ernstige psychische aandoeningen (EPA): Kwantitatieve resultaten van een gemengde methoden onderzoek, GGNet, Wetenschapsmiddag, Warnsveld (2021)	12
- *Workshop* NET voor co-morbide PTSS bij patiënten met ernstige psychische aandoeningen (EPA). Resultaten van een gemengde methoden onderzoek, Voorjaarscongres, Maastricht (2022)	16
Teaching activities	
Lecturing	
- Organisatie en deelnemer cursus in company Clinician-Administered PTSD scale for DSM-5 (CAPS-5) Centrum '45 & GGNet, Apeldoorn (2014)	16
- Bij- en nascholing voor psychiaters: 1. Trauma en trauma-gerelateerde stoornissen bij ernstige psychiatrische aandoeningen. 2. Mixed methods onderzoek: evaluatie van veranderingen na Narratieve Exposure Therapie (NET) & R. Jongedijk presentatie over NET, GGNet, Warnsveld (2015)	24
- Organisatie cursus Narratieve Exposure Therapie (NET) incompany, Centrum '45 & GGNet (2015)	8
- Caput college: Trauma gerelateerde dissociatie en dissociatieve stoornissen. Wolfheze, 2015, 2017	16
- Organisatie cursus en uitvoering trauma-gerelateerde dissociatie en complexe dissociatieve stoornissen: diagnostiek en behandeling, 3-daagse cursus, M. Mauritz & R. Vroon GGNet, Warnsveld (2016)	32
- Klinische lessen: Verpleegkundige zorg bij intensieve PTSS behandeling & Dissociatie volgend op traumatische stress, GGNet Zutphen (2018)	24
- Driedaagse scholing: Screening en diagnostiek van psycho-trauma en PTSS; Narratieve Exposure Therapie (NET) en andere traumagerichte behandelingen; Wetenschappelijk onderzoek naar effect van NET bij EPA, UGent, Gent (2021)	36
Total	**655**