Narrative Therapy and Quality of Life in Functional Neurological Disorder

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NARRATIVE THERAPY AND QUALITY OF LIFE IN FUNCTIONAL NEUROLOGICAL DISORDER

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Abstract

Functional Neurological Disorder is a severely disabling and stigmatized condition in which motor or sensory neurological symptoms cannot be attributed to a known neurological condition and are considered to be psychological in nature. Cognitive behavioral therapy improves depression and neurological symptoms for some patients, but many do not respond to therapy, and treatment adherence is extremely low. Narrative therapy is a psychotherapeutic model based in reframing one’s life story, and it is associated with decreased self-stigma and improved treatment adherence and engagement, but it has not been studied in Functional Neurological Disorder. In this randomized controlled trial, we will compare health-related quality of life, self-stigma, and somatic outcomes among adults with Functional Neurological Disorder who receive cognitive behavioral therapy plus narrative therapy versus cognitive behavioral therapy alone. These results stand to provide new insights to guide multimodal therapeutic approaches in treating this challenging disorder.
CHAPTER 1: INTRODUCTION

1.1 Background

Functional Neurological Disorder (FND), also known as Functional Neurological Symptom Disorder and formerly known as Conversion Disorder,\(^1\) is a condition that causes altered sensory or motor function that cannot be explained by a known organic neurological condition. This is a heterogenous disorder, including broader subtypes of motor, sensory, speech, and seizure disorders, with narrower subtypes therein. FND was historically known as Conversion Disorder, referring to the concept of psychological stressors being converted to physical neurological symptoms,\(^1\) and it falls under the category of “Somatic Symptom and Related Disorders” in the Diagnostic and Statistical Manual of Mental Disorders 5\(^{th}\) Edition-Text Revision (DSM-5-TR).\(^1\) While the disorder was previously considered to be completely psychogenic in nature due to significant overlap with psychiatric comorbidities and traumatic life experiences including but not limited to childhood abuse, neglect, and violence, among others,\(^2\) recently expanding evidence suggests that it is better explained using a biopsychosocial framework of predisposing, precipitating, and perpetuating factors\(^3,4\) and the DSM-5 no longer requires an underlying psychiatric precipitant to be identified for a positive diagnosis.\(^1\) FND is a severely disabling condition which is associated with high rates of healthcare usage, unemployment, and reliance on government assistance.\(^5\) There is also a growing body of evidence that at least some subtypes of FND are associated with elevated mortality rates.\(^6\) The long-term prognosis for FND is unfavorable, with studies overwhelmingly reporting constant or worsened symptom burden and quality of life at a wide range of follow up durations.\(^7,8\)
There is a dearth of research and education surrounding this condition disproportionate to its prevalence, with reports ranging from 10-15% of outpatient neurology clinic cases to the second most common diagnosis in neurology. These estimates are complicated by the fact that FND can coexist with organic neurological disorders such as epilepsy and multiple sclerosis. Moreover, the diagnosis of FND is frequently delayed and prolonged, with functional seizures for example requiring an average of seven years from symptom onset to be correctly diagnosed. Even then, FND is a challenging diagnosis for providers to communicate to patients. Due to stigma around psychological problems and a lack of understanding on the part of many patients and providers alike, patients are often left feeling confused and dismissed by their providers at the time of diagnosis. Healthcare providers report receiving little to no formal education in FND and endorse personal biases based on inaccurate beliefs that patients are feigning symptoms, leaving patients vulnerable to delayed diagnosis and improper treatment. Poorly delivered or dismissive diagnoses are associated with lower patient acceptance of the diagnosis and label-avoidance, an internalized aspect of stigma that manifests as a patient’s hesitation or resistance to an FND diagnosis due to its association with stereotypes and social rejection. Even when a patient does accept their FND diagnosis, self-stigma – a phenomenon in which a person begins to accept negative stereotypes of their illness as true and descriptive of themselves – can negatively affect self-esteem, quality of life, and treatment adherence.

Patient adherence to psychotherapy in functional seizures, one subtype of FND, has been found to be as low as 40% at four months and dropping to as low as 14% by 18-month psychiatric follow-up. Cognitive Behavioral Therapy (CBT) has been shown
to be effective in improving somatic symptoms, quality of life, and psychosocial function for many patients with FND, but there is still a significant minority of patients who do not benefit in trials of CBT, and some subtypes of FND such as functional movement disorder show less of a response to CBT alone. There is a gap in the literature regarding alternative or complementary types of psychological interventions that providers might use to treat patients with FND.

In individuals with schizophrenia spectrum disorders or other severe mental illness, varying models of narrative therapy – a structured processing and writing of one’s own life experience – has been associated with reduced self-stigma, improved self-esteem, and increased quality of life. Narrative therapies tend to follow similar curricula of self-identification, psychoeducation, restructuring of cognitive biases, and storytelling as a way of externalizing illness and reclaiming agency over one’s life events. This has also been demonstrated to be an effective therapeutic intervention among patients with major depressive disorder and survivors of interpersonal violence, two groups that overlap heavily with FND; however, narrative therapy has not yet been studied among patients with FND. The impact of CBT on self-stigma has not been established. Because self-stigma is consistently associated with non-adherence with psychotherapy and because narrative therapy improves both self-stigma and treatment adherence in other related psychiatric disorders, adding narrative therapy as an adjunctive therapy in FND may improve both self-stigma in FND and treatment adherence. Because adherence with psychotherapy is associated with improved somatic symptoms and quality of life among patients with FND, narrative therapy may also improve these outcomes in FND. The novelty and relevance of this proposed study to Physician Assistant practice is
its potential to introduce a new evidence-based treatment modality for a common and highly disabling but stigmatized and underrated disorder. This is a particularly promising treatment modality because it specifically addresses the problem of self-stigma which has been shown to be a common and harmful problem among patients with mental illness and can manifest as label-avoidance and treatment nonadherence,31 two prevalent phenomena in the FND population. Currently only one modality of psychotherapeutic treatment for FND is supported by rigorous multi-center randomized trials, and many patients do not respond to this particular treatment modality.22

1.2 Statement of the Problem

Functional Neurological Disorder accounts for as many as 15% of new neurology appointments4 and is associated with high medical costs, significant use of medical services, low quality of life, and high mortality.6,18 CBT is the most studied FND treatment and is known to reduce functional seizure frequency and to improve quality of life and global functioning for some patients,19 but it has been less effective alone with other subtypes of FND. The impact of CBT on self-stigma has only been explored in 2 small studies of group CBT for mood disorders in the specific context of Japanese or Chinese culture.32,33 Currently, CBT is the only psychotherapeutic modality for the treatment of FND with efficacy demonstrated by a high-quality multi-center randomized trial. Yet even in trial conditions, many patients with FND do not experience benefits from CBT alone. Narrative therapy has been found in other populations to address some of the factors which underlie barriers to recovery in FND such as self-stigma and nonadherence to treatment. Thus, it is worth studying narrative therapy’s effect as an adjunct to CBT on quality of life as it relates to physical and mental health in FND.
1.3 Goals and Objectives

In this proposed single-blind parallel groups randomized controlled trial, we aim to explore the effect of narrative therapy as an adjunct to the standard CBT on the health-related quality of life in adults with FND. Individuals with FND will be recruited from Yale New Haven Health System (YNHHS) inpatient neurology units, epilepsy monitoring units, and outpatient neurology clinics, and randomized to receive 12 weeks of narrative therapy plus CBT versus the usual CBT alone. Our two primary outcomes will be the mean difference from baseline to end of treatment in the physical and mental component summaries of health-related quality of life, with the mean differences from baseline to 6-month follow up as secondary outcomes. Our other secondary outcomes will include adherence with CBT as well as the mean differences in self-stigma and somatic symptoms from baseline to end of treatment and from baseline to 6-month follow up.

1.4 Hypothesis

We hypothesize that in adults with FND, there will be a statistically significant improvement in physical and mental health-related quality of life following a 12-week course of narrative therapy in conjunction with CBT when compared to CBT alone.

1.5 Definitions

*Cognitive Behavioral Therapy*: a form of psychotherapy based on the core principles that psychological problems are in part based on distorted or unhelpful thought processes which lead to unhelpful learned behaviors, and that by learning to recognize and reevaluate one’s thought distortions, one can develop more effective coping
mechanisms and change unhelpful behaviors, thereby relieving psychological symptoms and improving functioning in daily life.34

Functional Neurological Disorder A disorder which causes symptoms of altered voluntary motor or sensory function which are clinically incompatible with known neurological or medical conditions, and which are not better explained by another medical or mental disorder. These symptoms must be significant enough to necessitate medical assessment or cause significant distress or impairment in social, occupational, or other key areas of functioning. Subtypes include:

Motor: weakness, paralysis, gait abnormalities, tremor, jerks, or dystonic movements.

Sensory: altered, reduced, or absent skin sensation, vision, or hearing.

Speech and swallowing: reduced or absent speech volume, altered speech articulation, prosody, or fluency, or a sensation of a lump in the throat.

Seizures: episodes of apparent unresponsiveness with or without limb movements which may resemble epileptic seizures, syncope, or coma.¹

Narrative Therapy: a form of psychotherapy developed by Michael White and David Epston³⁵ based on the principles that people are the experts on their own lives, that problems are separate from people, and that people have skills and competencies that can help them change their relationship with the problems in their lives. Narrative therapy uses a structured story-telling approach that links the writer’s significant life experiences by theme and plot, and places them in larger social, political, and culture contexts. The goal is to externalize problems and build a separate multi-faceted self-identity, effectively “re-authoring” one’s life and regaining the power over one’s narrative.³⁵,³⁶ Narrative
therapy has been adapted to specific populations and settings by therapists and researchers since its development in 1990.

1.6 References


CHAPTER 2: REVIEW OF THE LITERATURE

2.1 Introduction and Methodology

A methodical literature review was conducted between June 2022 and September 2023 using APA PsychBooks, APA PsycINFO, Embase, Ovid Medline, PubMed, and Scopus. Search strategies were discussed with a consulted academic librarian. Search parameters included combinations of the following key terms: “functional neurological disorder”, “FND”, “functional neurological symptom disorder”, “conversion disorder”, “cognitive behavioral therapy”, “CBT”, and “narrative therapy”. Further search terms included “functional movement disorder”, “functional seizure”, “psychogenic non-epileptic seizure”, “PNES”, “psychotherapy”, “self-stigma”, “internalized stigma”, “quality of life”, and “somatic symptom”. Relevant sources were identified by title and abstract, and additional sources were found by hand review of those articles’ reference lists. Studies included in this literature review include meta-analyses, systematic reviews, randomized controlled trials, quasi-experimental studies, uncontrolled trials, feasibility studies, pilot studies, prospective studies, retrospective studies, and qualitative observational studies.

2.2 Review of Empirical Studies

2.2.1 Health-Related Quality of Life in Functional Neurological Disorder

FND has been repeatedly demonstrated to be strongly associated with poor health-related quality of life. A 2016 systematic review by Jones et. al of 14 studies from inpatient and outpatient neurological and psychotherapeutic settings throughout 4 countries described significant associations between low health-related quality of life and depression, somatic symptoms, dissociation, and escape-avoidance coping strategies in
patients with functional seizures. Comorbid depression (with prevalence of up to 85%) and a high tendency to experience somatic symptoms may be contributing factors to poor quality of life in functional seizures. FND is also associated with disproportionately high rates of other health concerns. A 2019 case-control study by Jennum et al. found significantly higher rates of morbidity in 17 of 21 World Health Organization disease groups in patients with functional seizures when compared to individuals without functional seizures, including metabolic and cardiovascular disease, with the strongest associations being psychiatric disorders, nervous system disorders, and somatoform conditions. Patients with functional movement disorder report similarly low quality of life. Baseline data from questionnaires in a Gelauff et al. study of patients with functional movement disorder found a median rating of 3/5 self-reported quality of life with no differences between the 5 dominant symptom groups surveyed. Additionally, a Vechetova et al. study in 2018 found associations between lower quality of life and depression, anxiety, pain, cognitive complaints, and apathy in patients with functional movement disorder, but notably no association with motor symptom severity scores. This is a similar finding to an Anderson et al. study of patients with functional movement disorder compared to patients with Parkinson Disease, which found lower self-rated quality of life in the functional movement disorder group despite reporting the same levels of disability and physical health as the Parkinson Disease group. Additionally, the functional movement disorder group reported significantly higher ratings of depression, anxiety, and somatic symptoms.

In interviews with patients with functional motor disorder, a 2020 qualitative study by Nielsen et al. identified common themes within their experiences and
perspectives that elaborate on aspects of quality of life: physical and emotional burdens of living with the disorder, difficulty obtaining a diagnosis, dissatisfaction with a psychological explanation for their symptoms, abandonment by healthcare providers, iatrogenic detriments, and feelings of powerlessness. Patients discussed their physical restrictions negatively affecting their ability to complete activities of daily living, maintain employment, and attend to family duties. Many patients reported subsequent experiences of social isolation and withdrawal due to inaccessibility of public spaces, embarrassment regarding their illness, or limitations from symptom burden. Feelings of powerlessness were prevalent in this group due to perceived abandonment or dismissal by their healthcare providers and a lack of understanding regarding their symptoms and diagnosis. A survey of 538 medical professionals conducted by Lehn et. al unfortunately legitimizes these perceptions of dismissal; 19% responded that they would not see patients with FND if they had a choice, 37% responded that they did not have enough time to deal with patients with FND, and only 51% disagreed that these patients are manipulative. This survey also found that a mere 14% of healthcare professionals felt they received adequate training about FND and only 34% knew how to diagnose it. It is likely that the consequences of stigma are self-propagating in the field of FND; lack of research and knowledge leads to stigma within healthcare, and the resulting attitudes toward the disorder lead to low prioritization and funding of research. This is particularly concerning because FND is associated with years-long delays of diagnosis and because the condition’s already poor prognosis is even worse so with longer symptom duration.
Furthermore, a 20-year retrospective cohort study conducted by Nightscales et. al\textsuperscript{6} of 5508 patients admitted for video-EEG monitoring found that patients with functional seizures had a standardized mortality rate 2.5 times greater than the general population and a relative risk of mortality as high as 8.6 when compared to the general population, with no difference in death rates between patients with functional seizures and medication-refractory epilepsy. In patients with functional seizures who were under the age of fifty, 44.4\% of deaths with a known cause were attributable to drug- or medication-related suicide or accidental poisoning, independent of the presence of psychiatric comorbidities.\textsuperscript{6} Similarly, Jennum et. al found a mortality rate of patients with functional seizures that was 3 times that of individuals without functional seizures.\textsuperscript{18} With a lack of clarity surrounding cause-effect relationships between FND and overwhelming rates of medical and psychological comorbidities, there is a clear need for FND research to be better prioritized in order to address improvement of the health and lives of these individuals.

### 2.2.2 Cognitive Behavioral Therapy in Functional Neurological Disorder

There is a paucity of research surrounding FND in general, and there has been only one adequately powered multi-center randomized controlled trial of CBT as a treatment for functional seizures. The CODES trial (cognitive behavioural therapy for adults with dissociative seizures), Goldstein et. al compared functional seizure-specific CBT plus standardized medical care (SMC) to SMC alone in effectiveness of functional seizure frequency reduction.\textsuperscript{22} Three hundred and sixty-eight patients were randomized to one of two groups, and outcomes were assessed at 12 months.\textsuperscript{22} They found that at 12 months, there was no statistically significant difference between the groups in regard to
monthly functional seizure frequency, but the CBT plus SMC group showed improvement in health-related quality of life, psychosocial functioning, and somatic symptoms. This group also rated their seizures as less burdensome with longer periods of seizure freedom in the previous 6 months.\textsuperscript{22} Self- and clinician-rated clinical improvement were also greater in the CBT plus standardized medical care group.\textsuperscript{22} The secondary analysis of the CODES trial that Goldstein et. al conducted using outcome data from 6 months post-randomization did show a reduction in monthly seizure frequency in addition to favorable outcomes for 12 of 13 measured mood, health, functioning, and quality of life outcomes for the CBT plus SMC group.\textsuperscript{43} Of note, the 6-month mark was close to the end of CBT treatment. This information suggests that even without sustained change in seizure frequency, coping skills learned in CBT may have assisted patients in better tolerating their symptoms. Jones et. al argue that rather than freedom from seizures, improved psychosocial functioning, quality of life, and decreased depression may be more relevant and realistic goals of therapy for these patients.\textsuperscript{37}

Targeting similar outcomes, Calderbank et. al conducted a prospective study of patients with FND who underwent an integrated psychotherapy model which was developed with elements of CBT, trauma-focused therapy, and somatic-focused interventions in consideration of the high overlap of FND and PTSD symptoms.\textsuperscript{44} While this study was uncontrolled and suffered from a substantial lack of post-therapy data, they did find that three times as many participants reported improved PTSD symptoms when compared to those that reported worsening symptoms (30\% and 9\%, respectively).\textsuperscript{44} They discussed the worsening PTSD symptoms in the 9\% to be possibly attributable to an improvement in alexithymia – an inability to identify or describe one’s emotions, which
is widely prevalent in the FND population – to improved ability to identify somatic symptoms, or to distress following reactivation of traumatic memories. This study also found statistically significant improvements in outcome measures for depression, anxiety, somatic symptoms, health-related quality of life, and social functioning. This evidence supports a role for multimodal psychotherapies in the treatment of FND. A 2022 integrative review by Cobb et. al on smaller studies of non-pharmacologic interventions for treating functional seizures found statistically significant improvement in seizure frequency with many techniques of psychotherapy, including several multimodal therapies that used various elements of CBT, motivational interviewing, mindfulness therapy, psychoeducation, interpersonal therapy, dialectical behavioral therapy, acceptance and commitment therapy, prolonged exposure therapy, family intervention, or self-help therapy. Therapies that utilized multiple dimensions of treatment were found to be the most effective in reducing seizure frequency, though studies that found no difference in seizure frequency still saw significant changes in other aspects of functioning or quality of life.

Available studies of CBT in FND subtypes other than functional seizures have been smaller-scale with lower quality evidence, and while CBT was associated in reduced symptom severity in functional movement disorders for most studies, effects were not often found to persist at follow-up. Additionally, a majority of studies have utilized multidisciplinary treatments including neurology, psychiatry, physical therapy, or occupational therapy in addition to psychotherapy, making it difficult to ascertain the magnitude of effect CBT contributed to symptom improvement. Functional tremor, the most common functional movement disorder, was found to respond particularly well to
CBT in a prospective cohort study of 15 patients by Espay et al comparing tremor severity and fMRI images before and after a 12-week course of CBT. Not only did they see remission or near-remission in 73.3% of the cohort but also a decreased activation in an area of the brain that is involved in emotion processing and which has been correlated with alexithymia when overactivated.

2.2.3 Adherence to Treatment in Functional Neurological Disorder

Adherence to treatment in patients with FND is a well-established challenge for providers in developing appropriate and accessible treatment plans. Tolchin et al conducted three studies regarding psychiatric and psychotherapeutic treatment adherence, association of functional seizure frequency with adherence, and association of motivational interviewing with adherence. The first was a prospective cohort study of 123 patients with functional seizures to assess long-term adherence to treatment. Participants were scheduled for 4 outpatient psychiatry appointments, and while 80% of patients attended their first appointment, attendance progressively declined to 42%, 24%, and 14% over the remaining visits. In another prospective cohort study, Tolchin et al expanded on this research to examine the association of patient adherence to treatment with clinical outcomes. One hundred and five patients with functional seizures were referred to 12 sessions of weekly psychotherapy and 4 neuropsychiatry appointments, with criteria for adherence being attendance at 8 psychotherapy sessions over 16 weeks. Of patients who provided follow-up, only 40% met this criteria. 61% of non-adherent patients achieved ≥50% reduction of seizure frequency compared to 84% of adherent patients. Adherent patients also saw a statistically significant improvement in quality of life and reduction of emergency department utilization compared to non-adherent
patients. In a randomized controlled trial of a separate cohort, Tolchin et. al found a significant improvement in adherence to psychotherapy (65.4% vs. 31.0%) and significant decrease in functional seizure frequency (76.2% vs. 34.8%) in the group of patients randomized to one 30-minute session of motivational interviewing when compared to a control group attending psychotherapy without a session of motivational interviewing. This evidence supports the merit of exploring complementary techniques to optimize treatment engagement and success.

LaFrance et. al and Tilahun et. al explored the utilization of telehealth in two prospective cohort studies of patients with functional seizures. With the severe shortage of mental health professionals throughout the industry, it is common for patients to be faced with prohibitively long travel times for routine appointments. Individuals with FND also often have transportation challenges due to symptom burden and are frequently unemployed, which can be a significant barrier to healthcare access. Tilahun et. al followed 257 patients who were offered 12-week psychotherapy courses with the option of in-office or telehealth appointments, and they found that the telehealth visits were 2.4 times more likely to be attended and less likely to be canceled. There was no difference between the groups regarding no-call no-show rates. LaFrance et. al also conducted a 12-week course of weekly psychotherapy sessions with a focus on treatment outcomes. They found that functional seizure frequency was reduced by an average of 45.7% each month during treatment, with an average weekly seizure count nearing 0 by month 6. Secondary outcomes of global functioning, quality of life, depression, and anxiety also improved, and adherence to treatment was >80% in this cohort.
However, attendance at appointments cannot be equated with full engagement in therapy. While the previously mentioned CODES trial also experienced a higher adherence rate at 75%, defined as attendance at 9 of 12 CBT sessions, interviews conducted after the study reflected a common theme of hesitation or refusal by the participants to engage in CBT tasks due to emotional avoidance, a tendency to think or act in ways that avoid uncomfortable or distressing emotions and experiences. Strongly tied to alexithymia, emotional avoidance is a well-documented phenomenon with individuals with FND and has been linked to impaired psychological resilience, a measure of stress coping ability which has been proposed to play a role in the biopsychosocial model of FND as a predisposing or perpetuating factor. Emotional avoidance is associated with poorer prognosis in FND and can prevent patients from initiating therapy or continuing with treatment once difficult topics are exposed, so it is no surprise that it is also associated with lower health-related quality of life and maintenance of depression. Thus, not only is adherence to treatment a valuable and necessary area of research for effectively helping patients with FND, but so is meaningful engagement with treatment methodology.

2.2.4 Narrative Therapies for People with Mental Illness

Narrative therapy is a psychotherapy model centered on reframing one’s life story and experiences. Since its development by White and Epston, it has been adapted into multiple manualized therapies and adjusted to treat specific populations, but never with patients with FND. The elements of narrative therapy include identifying crucial experiences in one’s life, challenging one’s own beliefs or assumptions about the associated circumstances, externalizing elements of one’s problems or negative
experiences, and rewriting stories from a renewed perspective.\(^{35}\) The underlying theory of this therapeutic modality is that language and narratives are essential for constructing, organizing, and making meaning of one’s knowledge and experiences.\(^{52}\) The majority of published narrative therapy research is based on interventions with patients with schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorder, and the research is focused largely on challenging participants’ internalized stigma of mental illness (“self-stigma”). In a systematic review and meta-analysis by Livingston and Boyd, self-stigma was found to have a substantial negative association with hope, self-esteem, empowerment, quality of life, and treatment adherence.\(^{53}\) This is consistent with other studies that demonstrate self-stigma as an important cause of non-adherence with psychotherapy in psychiatric illnesses such as major depressive disorder and bipolar disorder.\(^{54,55}\) Qin et. al describe a concept in self-stigma of mental illness called the “Why Try effect,” a feeling of futility in the efforts toward recovery or goals as a result of internalized stigma and decreased self-esteem.\(^{31}\) Patients with FND are particularly disposed to internalizing stigma due to pervasive external stigma in almost all realms of life including occupational, social, familial, and healthcare settings,\(^{15}\) and while it has not yet been quantitively studied among patients with FND, multiple qualitative studies and reviews suggest that self-stigma is a serious issue in this patient population.\(^{14,15,56-58}\) Considering this alongside the evidence that non-adherence is a common problem for patients with FND,\(^{17}\) narrative therapy may be a useful adjunctive treatment for this population as well.

In a randomized controlled trial of a manualized method of narrative therapy called Narrative Enhancement and Cognitive Therapy (NECT), Yanos et. al randomized
170 individuals with schizophrenia or schizoaffective disorder to receive either NECT or supportive group therapy to assess the efficacy of NECT in reducing self-stigma. Over the course of one year, a statistically significant improvement was seen in self-stigma in the NECT group, with effects being most apparent at 3- and 6-month follow-up. The NECT group also showed a decrease in avoidant coping strategies, were more engaged in treatment, and had a lower dropout rate than those in supportive group therapy. This complemented previous findings of NECT’s positive effect on self-stigma, self-esteem, and hope. In a 2023 randomized controlled trial by Huang et al using NECT with patients with schizophrenia, no difference in perceived stigma was seen following 12 weeks of cognitive restructuring; however, after an additional 8 weeks of narrative enhancement, self-stigma was significantly improved. This suggests a cumulative benefit to using cognitive and narrative methods together.

Narrative and autobiographical therapies in general have been found to have positive effects on quality of life in populations such as older adults, refugees, and individuals with PTSD or depression, but NECT specifically has shown mixed data on quality of life. A 2020 randomized controlled trial by Shakeri et al found significant reductions in depression and anxiety in patients with amphetamine use disorder following 10 sessions of narrative therapy, but there was no significant difference in mean quality of life score in either the treatment or control group. Hansson et al also found significant differences in improvement in self-stigma and self-esteem when compared to control groups but no differences in quality of life. In contrast, Roe et al did see improved quality of life for patients with severe mental illness in the NECT group when compared to their Treatment As Usual control arm. Another modality of narrative therapy called
Narrative Cognitive Therapy (NCT), manualized based on Oscar Gonçalves’ writings,\textsuperscript{52} was compared to CBT in adults with major depressive disorder in a 2017 randomized controlled trial by Azevedo da Silva et. al.\textsuperscript{28} They found significant improvement in all domains of quality of life within both groups but no significant difference between them.\textsuperscript{28} Additionally, like other studies, they observed a higher dropout rate in the CBT group when compared to the NCT group.\textsuperscript{28} These inconsistent outcomes may be due to multiple factors such as varying methods of delivery, settings, populations, and rating scales among the studies.

Considering that multi-modal therapeutic models have shown significant improvement in quality of life and that narrative therapies have shown inconsistent results in quality of life across populations when studied alone, there is a possibility that the benefits of narrative therapy can be a useful adjunct to other forms of therapy. Since a decrease in self-stigma is associated with both a decrease in emotional avoidance and an increase in treatment adherence – both of which are challenging aspects of FND experience and treatment – narrative therapy may be able to function as preparation or adjunctive treatment for a patient with FND, allowing them to engage more fully in CBT work.

2.3 Review of Relevant Methodology

2.3.1 Study Design

The highest-quality data in the limited number of studies of CBT for patients with FND came from randomized controlled trials with parallel groups. Other study designs included quasi-experimental studies, uncontrolled prospective cohort studies, and retrospective qualitative studies. Goldstein et. al and LaFrance et. al conducted the only
multi-center CBT studies to date. Various control groups included standard neurological treatment, self-help groups, psychoeducation, waitlists, medication, or no intervention, making comparisons among studies challenging. Almost all quasi-experimental studies used a treatment group only. Blinding is a common limitation for almost all trials of psychotherapeutic interventions due to the nature of the treatments. As such, blinding was limited within CBT studies; patients and therapists were unable to be blinded to group allocation, but data collectors, statisticians, and fidelity raters were blinded in many cases. Most studies did not collect follow-up data, but when they did, it was most often at 6 or 12 months, with a range of 1-24 months.

Narrative therapy studies were similarly limited and heterogenous in design. Most were randomized controlled trials, and Huang et. al conducted the only multi-center study. Populations and control groups were inconsistent across trials. Patients with schizophrenia spectrum disorders were the most studied population, but patients with bipolar disorder, major depressive disorder, or substance use disorder, survivors of interpersonal violence, refugees, and individuals who had attempted suicide were also studied. Control groups received either supportive group therapy, routine psychiatric care or treatment as usual, psychoeducation, CBT, or were placed on a waitlist. Narrative therapy studies were also only able to be blinded to data collectors, statisticians, and fidelity raters. Follow-up duration ranged from 1 week to 31 months with no mode.

A strength of some studies was an allowance for flexible appointment scheduling, such as defining adherence as 8 sessions over 16 weeks rather than expecting patients and providers to follow a precise schedule for numerous consecutive weeks. Other studies used telehealth for psychotherapy sessions. Flexible scheduling is unfortunately not
feasible with a structured group course in narrative therapy, but this proposed study will allow for flexible scheduling and telehealth for CBT sessions.

2.3.2 Study Setting

Study participants with FND were recruited from various settings including inpatient neurology units, epilepsy monitoring units, and outpatient neurology and/or psychiatric clinics. The CODES trial, the largest of the CBT studies, recruited participants from 27 neurology or epilepsy services in three countries and provided services in 17 outpatient neuropsychiatric or liaison services, but the majority of studies recruited and treated patients in fewer than 7 sites. Psychotherapy was delivered on an outpatient setting with two studies providing a telehealth option. Most studies utilized their own psychotherapists with a few exceptions that permitted some patients to see community therapists of their choice based on geographical distance or preference. Narrative therapy studies recruited primarily from outpatient mental health programs, inpatient psychiatry units, psychiatric long-term care facilities, and outpatient psychiatric clinics. Interventions were conducted in outpatient clinics, inpatient psychiatry units, multidisciplinary outpatient mental health settings, and substance use disorder treatment programs.

The various recruitment and treatment settings illustrate particular strengths for developing future studies. For example, inpatient treatment delivery provided more reliable program completion, but outpatient delivery allowed for better generalizability regarding treatment acceptability and adherence considering most patients engaging in psychotherapy will be treated in an outpatient setting. Additionally, studies often
recruited from several types of settings and even multiple states or countries, increasing external validity.

### 2.3.3 Selection Criteria

All studies used consecutive or convenience sampling. Due to the cognitive requirements of the psychotherapeutic interventions, most studies excluded patients with intellectual disabilities. Patients were also excluded if they were logistically unable or unwilling to engage in required tasks such as keeping seizure diaries, completing questionnaires, or attending treatments. Some studies were limited to patients who were fluent in the languages of the treatment team in order to control for any confounding that could result from the use of language interpreters.

Studies for patients with FND were often separated by diagnosis of functional seizures or any other subtype of FND, with very few studies combining the groups. Functional seizure diagnoses were verified by video electroencephalogram (EEG), or when unavailable, the clinical judgment of two or more physicians with expertise in the diagnosis of seizures and/or neurological disorders. Other FND diagnoses were verified by clinical exam, often by two or more physicians. The CODES study\(^\text{22}\) employed a delay of 3 months after diagnosis to ensure that participants’ functional seizures had not remitted before the data collection began, and only enrolled patients with comorbid epilepsy if they had not experienced an epileptic seizure for over 12 months. Studies of patients with functional movement disorder similarly aimed to reduce confounding by excluding patients with comorbid neurological or other movement disorders. However, many individuals with one subtype of FND also experience other somatic symptoms, so confounding can be challenging to control for. Due to the large overlap of FND with
PTSD, depression, and anxiety, patients with psychiatric comorbidities were not typically excluded unless they had an active substance use disorder or expressed suicidality. In narrative therapy studies of patients with mental illness, diagnoses were verified by the most updated DSM criteria and interviews by mental health clinicians, and since most studies were diagnosis-specific, exclusion criteria by psychiatric comorbidity varied.

Relevant strategies that will be applied to this proposed study include stratification by FND subtype rather than limiting the population to certain diagnoses, exclusion of patients with comorbid seizure or movement disorders that are not functional in etiology, and exclusion of patients with specific psychiatric comorbidities only if there are associated safety concerns or if they interfere with the completion of individual cognitive behavioral therapy regimens.

2.3.4 Exposure

Psychotherapeutic interventions in the included studies varied in curriculum development. LaFrance et. al\textsuperscript{19} and Goldstein et. al\textsuperscript{22} utilized their own manualized CBT-informed psychotherapy as described by psychiatrist Aaron Beck\textsuperscript{62} with adaptations for the management of functional seizures. LaFrance et. al\textsuperscript{19} created a CBT-informed regimen which included elements of motivational interviewing and additional psychotherapeutic modalities, while Goldstein et. al\textsuperscript{22} followed a classic CBT regimen without other added modalities. Therapists were trained in these methods and provided with fidelity feedback based on recordings of sessions. Some future studies followed the same protocols, and others relied on the expertise of psychotherapists with extensive knowledge of traditional CBT practices. The studies that allowed for patients to see community therapists contacted those therapists in advance to discuss therapy principles.
and methods. The number of psychotherapy sessions ranged from 7 to 20 with a mode of 12. Most studies used 1-hour sessions scheduled weekly or within a timeframe of 4-5 months.

The majority of narrative therapy studies followed the NECT manual as developed by Yano et al.63 This is a structured 20-week program with weekly 1-hour group sessions with specific cognitive or narrative-enhancing topics and goals for each session.63 Other narrative therapy modalities were developed by individual studies based on the writings of White and Epston35 and used 7, 8, 10, or 12 weekly 1 or 2-hour sessions.

There are several elements of these trials that will benefit the proposed study. While NECT was the most commonly studied and would therefore offer more accurate comparison across trials, the other narrative therapy modalities provide more flexibility in programming and time course which may improve treatment adherence. Furthermore, most CBT trials followed a 12-session format, and consistency between groups will increase internal validity. Lastly, many studies developed or utilized existing treatment manuals with associated fidelity assessments that evaluators used to provide feedback to therapists, which will be essential for studying such individualized and subjective treatments.

2.3.5 Outcomes

The included studies used a substantial number of outcomes with many measurement tools for each, likely due to the diversity of geographical locations and populations represented. Studies of functional seizures used a primary outcome of seizure frequency or treatment adherence with a variety of seizure-related secondary outcomes
including seizure freedom, seizure severity, seizure bothersomeness, and seizure reduction of $\geq 50\%$. Additional secondary outcomes often included health-related quality of life, psychosocial functioning, somatic symptom severity, depression symptoms, and anxiety symptoms. Studies that included other subtypes of FND used an array of primary and secondary outcomes largely falling into the categories of health-related quality of life, somatic symptom severity, psychosocial functioning, and psychiatric symptoms.

Self-stigma has not been routinely studied as an outcome in FND studies, though multiple small qualitative studies and narrative reviews included thematic outcomes of self-stigma, self-deprecation, low self-worth, and shame in patient interviews. The primary outcomes of narrative therapy studies were most often self-stigma or depression symptoms, with secondary symptoms including self-esteem, quality of life, psychosocial functioning, hope, and psychiatric symptoms. Self-stigma was measured using the Internalized Stigma of Mental Illness Inventory (ISMI)$^{64}$ or the Self-Stigma of Mental Illness Scale-Short Form (SSMIS-SF).$^{65}$ Health-related quality of life alone was measured by 9 tools, with the most common being the 8 domains or 2 summary measures (physical and mental components) of the 12-question or 36-Question Medical Outcomes Survey Short-Form General Health Survey (SF-12 or SF-36).$^{66}$ The SF-36 addresses 8 domains of quality of life that are then grouped into 2 larger summary measures called the physical component summary (PCS) and mental component summary (MCS)(see Appendix C). Scores are only measured by domain or component summary because they were not designed to be used as a single composite score.$^{67,68}$ Psychiatric symptoms were most often measured using the Patient Health Questionnaire (PHQ-9)$^{69}$ or Beck Depression Inventory–II (BDI-2)$^{70}$ for depression, Generalized Anxiety Disorder-7 scale
(GAD-7)\textsuperscript{71} or Beck Anxiety Inventory (BAI)\textsuperscript{72} for anxiety, and the PTSD Checklist for DSM-5 (PCL-5)\textsuperscript{73} for Post-Traumatic Stress Disorder symptoms. Somatic symptoms were nearly always measured using the Patient Health Questionnaire-15 (PHQ-15)\textsuperscript{74} which will be used in the proposed study.

Comparison across studies is challenging due to the wide range of outcome measurement tools utilized. The advantage of measuring health-related quality of life with the SF-36\textsuperscript{66} was the inclusion of mental and physical health-related items with the ability to operationalize outcomes by domain or summary measures. Additionally, many studies benefited from incorporating several psychiatric symptom or psychosocial functioning outcomes. The recent questioning of seizure freedom as the ultimate priority in treatment\textsuperscript{75} illustrates the importance of including secondary psychosocial outcomes in FND studies. Self-stigma will be measured with the ISMI rather than SSMIS-SF as it was more frequently used and will therefore increase comparability across studies.

### 2.3.6 Sample Size

There is a dearth of research on both FND and narrative therapy, and most studies were small and not powered to detect a difference between groups. The CODES trial was the first adequately powered randomized controlled trial of CBT’s effect on functional seizure frequency, enrolling 368 participants.\textsuperscript{22} Using data from their pilot study, they calculated a minimum sample size of 149 per arm in order to detect a moderate effect with 90% power when adjusted for potential therapist effects, pre-randomization data, and expected attrition.\textsuperscript{76} The smaller studies ranged from 15-210 patients based largely on previous studies’ calculations or recruitment ability. All studies used an alpha of .05.
Azevedo da Silva et al compared CBT to narrative therapy for management of depression symptoms in 97 patients.28 Their sample size was calculated with 80% power to detect a remission of 50% of depression symptoms in the CBT group and 70% in the narrative therapy group, requiring a total of 90 patients. Most narrative therapy studies were designed to measure self-stigma with the Internalized Stigma Of Mental Illness (ISMI) scale. Yanos et al used 80% power to detect a moderate effect size of 0.3, calculating a requirement of 130 participants or 65 per group, which they exceeded at a total of 170.27 Hansson et al also used 80% power but to detect a larger effect size of 0.6, which required 96 participants total.61 They aimed to recruit 115 participants to account for an expected loss of 15% and ultimately enrolled 106 participants.61 Other narrative therapy studies were small, but NECT specifically suggests that treatment groups include 4-8 participants so as to provide patients with effective oversight and support; therefore, some studies were limited in how many groups they could manage with limited numbers of trained therapists.

2.4 Conclusion

This literature review illustrates the paucity of research available for a severely disabling and stigmatized disorder. FND is a common condition with many phenotypes which often goes undiagnosed and untreated for many years. CBT has been the standard treatment for this challenging disorder to this point, but results are inconsistent across subtypes and treatment adherence is poor. Several systematic reviews have noted higher rates of symptom improvement and quality of life in studies that utilized multimodal treatments, suggesting that there is a need for therapies complementary to CBT. Narrative therapy has been found to decrease internalized stigma in patients with mental illness and
improve their active engagement in therapy. To this point, no studies have used narrative therapy as an intervention for FND though adherence and stigma are significant issues among this population. If CBT and narrative therapy show a cumulative effect on patients’ quality of life as treatment engagement and adherence improve, short-course group narrative therapy sessions could be used as an adjunct to standard care for patients living with FND.

2.5 References


68. Ware JE, New England Medical Center Hospital Health I. *SF-36 physical and mental health summary scales: a user's manual*. Health Institute, New England Medical Center Boston; 1994.


CHAPTER 3: STUDY METHODS

3.1 Study Design

The proposed study is a single-blind parallel groups randomized controlled trial that will compare the change in health-related quality of life scores of patients who receive standard individual CBT alone or standard individual CBT plus group narrative therapy. Recruited patients who are randomized to CBT alone will participate in 12 weekly 1-hour individual CBT sessions with a licensed psychotherapist who has at least 3 years’ experience with CBT as described by the writings of Aaron Beck. Patients randomized to CBT plus narrative therapy will participate in the same CBT treatment plan as well as 12 weekly 1-hour group narrative therapy sessions led by two licensed psychotherapists who are trained in a narrative therapy curriculum specific to this study (see examples in Appendix F). Consistent with previous studies, narrative therapy groups will not exceed 8 participants per group to allow for sufficient therapist attention. Patients will continue their individualized medical and psychiatric care plans as usual according to their respective treatment teams separate from this study. Research assistants who are blinded to intervention assignment will analyze data from participants.

3.2 Study Population and Sampling

The population studied will be adults with a diagnosis of FND as confirmed by video electroencephalogram (EEG) in the case of functional seizures or by 2 neurology physicians or advanced practice providers with at least 3 years’ experience diagnosing and treating FND in the case of non-seizure FND or unavailability of video-EEG. Patients will be excluded if they are younger than age 18, are currently participating in CBT or narrative therapy, have previously completed a course of narrative therapy, have a
comorbid seizure and/or movement disorder, or have an active substance use disorder. Additionally, patients will be excluded if they are cognitively or logistically unable to complete a 12-week course of narrative therapy or 12 sessions of CBT over 16 weeks, such as individuals with moderate, severe, or profound intellectual disability, major medical illness that would prevent attendance or engagement in treatment, or who are pregnant at > 20 weeks’ gestation. To maximize patient safety, patients who express active suicidal or self-harm ideation or attempts will be excluded from the study.

This study will utilize consecutive sampling. All patients from Yale New Haven Health System (YNHHS) outpatient neurology clinics, inpatient neurology units, and epilepsy monitoring units who meet inclusion criteria will be invited to participate. This includes Yale New Haven Hospital, Bridgeport Hospital, Greenwich Hospital, Lawrence and Memorial Hospital, and Northeast Medical Group.

3.3 Subject Protection and Confidentiality

All members of the research team will complete Human Research Protection Training, Health Insurance Portability and Accountability Act (HIPAA) training, and Good Clinical Practice training, and any other educational requirements as outlined by the Yale Human Research Protection Program (HRPP). The study protocol will be submitted to the Yale Institutional Review Board (IRB) for approval. Once the study is approved and initiated, research personnel will provide potential participants with written information outlining HIPAA privacy policies and descriptions, expectations, requirements, risks, and benefits of participating in the study. Research personnel will obtain signed written informed consent documentation from all participants prior to enrollment (Appendix A). Any paper copies of patient documentation will be stored in a
locked cabinet in the principal investigator’s YNHHS office. Electronic patient data will be coded using unique participant numbers and encrypted on a password-protected HIPAA-compliant YNHHS secure server only accessible to necessary research personnel.

3.4 Recruitment

Participants will be recruited from YNHHS outpatient neurology clinics, inpatient neurology units, and epilepsy monitoring units. Potential participants will be identified by physicians and advanced practice providers at these locations who will obtain verbal consent to refer the patients to the research team for screening. A research assistant will contact each referred patient in-person or by telephone to conduct or schedule a brief screening interview to determine if the patient meets inclusion or exclusion criteria. If the patient is deemed eligible to participate in the study, the research assistant will explain confidentiality practices and the purpose and design of the study in lay terms and invite the patient to schedule an in-office meeting. During this meeting, a physician or advanced practice provider with at least 3 years’ experience diagnosing and treating FND will verify the FND diagnosis using physical exam and chart review. A research assistant will also obtain baseline information and written consent to enroll in the study. If referral or enrollment numbers are found to be inadequate one month into the recruitment period, research investigators will consider expanding recruitment efforts to additional sites or programs including University of Connecticut, Hartford Healthcare, and Brigham and Women’s Hospital neurology facilities as the researchers have colleagues and collaborators in these systems.
3.5 Study Variables and Measures

The independent variable of this randomized controlled trial will be the assigned treatment. Participants will be randomized to either an intervention group receiving CBT plus narrative therapy, or to a control group receiving CBT alone. Physical and mental health-related quality of life will serve as the dependent variables, operationalized as the mean differences from baseline to end of treatment in the SF-36 physical component summary (PCS) and mental component summary (MCS) (see Appendices B and C) with secondary outcomes of the PCS and MCS mean differences from baseline to 6-month follow-up. Other secondary outcomes that will be assessed from baseline to end of treatment and from baseline to 6-month follow-up include the mean difference in self-stigma as measured by the Internalized Stigma of Mental Illness Inventory (ISMI)\textsuperscript{64} (Appendix D), and mean difference in somatic symptom severity as measured by the Patient Health Questionnaire 15-Item Somatic Symptom Severity Scale (PHQ-15)\textsuperscript{74} (Appendix E). Additionally, adherence to treatment will be measured dichotomously with adherence defined as attending 9 of 12 CBT sessions in 16 weeks.

Due to the subjective nature of the interventions and outcomes, there are many potential confounding factors. Personal demographics including but not limited to age, sex, gender, race, ethnicity, and family of origin may have a considerable effect on participants’ perspectives on mental illness and psychotherapy. Psychiatric comorbidities or barriers to healthcare access such as financial concerns or health insurance status may affect symptom management and severity throughout the course of treatment. Within the study, participants’ assigned therapists may serve as confounders based on patient-provider relationship or delivery of treatment.
3.6 Methodology Considerations

3.6.1 Blinding of Intervention

Due to the interactive nature of the intervention, neither participants nor therapists can be blinded to the group allocation. Patients will know which sessions they are attending, and therapists will know who they are treating. CBT therapists may not need to know if a patient is also receiving narrative therapy, but it is unlikely that patients will refrain from discussing topics during CBT sessions that were addressed or unearthed during narrative therapy sessions.

3.6.2 Blinding of Outcome

Research personnel who collect and analyze outcomes data will be blinded to group allocation so as to minimize information bias. Instances in which blinding is broken will be documented.

3.6.3 Assignment of Intervention

Participants will be assigned by a member of the research team to either the intervention or control group in a 1:1 ratio using a randomization computer software program.

3.6.4 Adherence

CBT and narrative therapists will monitor adherence weekly and report any absences to a designated research team member. Participants will have a choice of in-office or telehealth CBT sessions to reduce potential barriers to treatment access.

3.7 Monitoring of Adverse Events

Serious adverse events will be defined as events that are life-threatening or that result in injury, new disability, hospital admission, or death. This includes suicidal or self-
harm ideation or attempts. While not anticipated in this study and not reported in the literature, suicide and self-harm are serious concerns when participating in a therapy that addresses uncomfortable or traumatic experiences. CBT and narrative therapists will use their clinical expertise to monitor participants for communication and behavior suggestive of suicidal or self-harm risk. Patients expressing active suicidality will be directed or escorted to the emergency room for immediate psychiatric evaluation. Patients who are admitted for psychiatric hospitalization will be removed from the study.

3.8 Data Collection

Baseline data will be collected during the initial in-office meeting with research clinicians and staff. The research assistant responsible for collecting data will instruct the new participant in submitting data using the secure internet-based survey tool Qualtrics. Baseline characteristic data will include demographics, psychiatric comorbidities, medical comorbidities, FND diagnostic history, and social history. Baseline assessments will include the 36-Question Medical Outcomes Survey Short-Form General Health Survey (SF-36), the Internalized Stigma of Mental Illness Inventory (ISMI), and the Patient Health Questionnaire 15-Item Somatic Symptom Severity Scale (PHQ-15). At the end of the 16-week treatment period and again 6 months later, participants will be emailed an individualized Qualtrics link by a research assistant who is blinded to group allocation. The linked Qualtrics survey will consist of the SF-36, ISMI, and PHQ-15. If a participant has not completed the Qualtrics survey within one week of receipt, a research assistant will attempt to contact the participant by telephone and email up to a total of 7 times over a 2-week period before the participant is considered to be lost to follow-up.
3.9 Sample Size Calculation

There are two primary outcome variables of the proposed study: the mean differences from baseline to end of treatment in the physical component summary (PCS) and the mental component summary (MCS) of the SF-36. The null hypothesis is that there will be no difference in the PCS or MCS mean differences between participants who received CBT and those who received CBT plus adjunctive narrative therapy. Due to the dearth of available studies of both the population and the intervention, two SF-36 user’s manuals\textsuperscript{66,68} were used to determine appropriate sample size. These manuals provide sample size recommendations based on detectable point differences in each of the component summaries. These component summaries are norm-based t-scores with a mean and standard deviation of 50 ± 10 for the general population pre-intervention. For this study design, Ware et. al define a significant clinical difference as 5 points for each of the component summaries, correlating with a recommended sample size of 33 participants per group per component.\textsuperscript{66,68} Because this study will utilize both component summaries, the recommended sample size is 66 per group. This study will use a 2-tailed hypothesis with a power of 80% and an alpha of .05. Using the Power and Precision software by Biostat, Inc., a mean difference of 5 and a standard deviation of 10 require a sample size of 64, reasonably consistent with the recommended 66 by Ware et. al. Using the larger of the two recommendations and adjusting for a 30% attrition rate, a sample size of 94 participants per group or 188 total will be required.

3.10 Statistical Analysis

This study will use Intention-to-Treat analysis. The 2 primary outcomes of the PCS and MCS mean differences from baseline to end of treatment will be compared
between the CBT group and the CBT plus narrative therapy group using student t-tests with effect size calculated using Cohen’s $d$. This calculation will be repeated to compare the groups’ PCS and MCS mean differences from baseline to 6-month follow-up as secondary outcomes. Primary results will be stratified by FND subtype as a secondary analysis. To evaluate secondary outcomes of mean differences in self-stigma and somatic symptom severity scores, student t-tests and Cohen’s $d$ will be used to compare ISMI and PHQ-15 scores from baseline to end of treatment and from baseline to 6-month follow-up. Adherence will be evaluated dichotomously as adherent or non-adherent, with adherence defined as attending 9 of 12 CBT sessions over 16 weeks. The effect of potential confounding variables will be evaluated using a multiple linear regression model.

### 3.11 Timeline and Resources

- **Months 0-6:**
  - Complete IRB approval process
  - Hire research team/therapists
  - Obtain feedback on novel narrative therapy regimen from 5-8 experts in the fields of FND and narrative therapy
  - Revise narrative therapy regimen based on feedback

- **Month 7:**
  - Participant recruitment begins (Cohort A)

- **Months 8-12:**
  - Cohort A treatment
  - Cohort B recruitment

- **Months 13-17:**
  - Cohort B treatment
  - Cohort A follow-up

- **Months 18-22:**
  - 6-month follow-up
Participants will be enrolled in either cohort A or B, with each cohort undergoing randomization to an intervention arm or a control arm. There is no difference in curriculum, research team, or therapists between cohorts A and B; this timing is simply to allow for rolling recruitment in hopes of reducing loss to follow up due to delays and to reduce provider burden by requiring therapists to take on fewer patients at one time. Within a cohort, a narrative therapy course with 8 participants will begin every time that 16 enrollees are accumulated and randomized 1:1.

The investigators will develop a narrative therapy manual and accompanying fidelity assessment rubric based on the principles developed by Michael White and David Epston. The investigators will conduct 2 fidelity assessments per therapist by evaluating a randomly-chosen narrative therapy session, recorded with participants’ consent. Other than the investigators who will provide design and oversight of the project, required personnel for the research team will include 5-10 psychotherapists licensed in Connecticut who will provide either individual CBT or group narrative therapy with no crossover, and at least 2 research assistants for participant screening, data collection and entry, and statistical analysis. Multiple private spaces such as after-hours clinic waiting or meeting rooms will be required for several small groups of weekly narrative therapy sessions. Access to secure, HIPAA-compliant office equipment on secure healthcare-system networks such as computers, printers, and photocopiers will be required for data management and creation of informational or program materials for participants.
3.12 References

40. Kroenke K, Spitzer RL, Williams JBW. The PHQ-15: Validity of a New Measure for Evaluating the Severity of Somatic Symptoms. Psychosomatic Medicine. 2002;64(2)
CHAPTER 4: CONCLUSION

4.1 Advantages

The proposed study will be the first to examine the effect of narrative therapy in this population. Since the research team will design this specific narrative therapy regimen alongside experts in the fields of FND and narrative therapy, the intervention will be tailored to the population and investigators will expect a high degree of fidelity during assessments. The timeframe of the intervention is also advantageous. CBT and narrative therapy are both designed to be time-limited interventions, so the 6-month follow-up data will be useful in assessing any potential need for longer treatment courses or ongoing therapy.

An uncommon advantage of the proposed study is the inclusion of patients with any form of FND since many studies are divided into subtypes, most often functional seizures and functional movement disorders. By stratifying outcome data, any differential in effect among subtypes will be evaluated. Furthermore, exclusion criteria will be minimal in order to recruit from a realistically representative pool of participants with medical and psychiatric comorbidities, increasing the external validity of the study.

4.2 Disadvantages

The proposed study suffers from limitations that affect almost all psychotherapeutic trials. Narrative therapy and CBT are ultimately subjective and individualized by nature, so while manuals and fidelity assessments can minimize inconsistency, there is no single way to perfectly standardize the treatments. Additionally, outcomes are all subjective and self-reported, increasing the chance of information bias. Future studies could add objective functioning or symptom measures to be completed by
independent clinicians at the end of treatment and at follow-up. Another disadvantage lies in the single control group. This study would have stronger internal validity if it were to include a third group to participate in individual CBT plus weekly supportive group therapy in order to control for any effect that social group interaction may have on outcomes. Future studies could evaluate differences among multiple control groups or utilize group CBT sessions.

4.3 Clinical Significance

FND is a challenging condition for patients to live with and for medical providers to treat. CBT is the best-studied treatment to date, but its benefits are not universal and treatment adherence is low. FND is a frequently misunderstood disorder even among medical professionals, and external stigma from healthcare systems and larger social contexts can be internalized by patients, negatively affecting self-esteem, treatment adherence, and clinical outcomes. Narrative therapy has been found to be effective in improving self-esteem and depression symptoms in populations that have a high overlap with patients with FND, such as patients with major depressive disorder, PTSD, and survivors of interpersonal violence.\textsuperscript{25,26,81} If narrative therapy is effective in improving self-stigma and adherence among patients with FND, it could serve as a short-term adjunctive treatment to optimize meaningful engagement in CBT work. This study has the potential to change how medical providers prioritize treatment strategies in a complicated and under-studied condition.
4.4 References


APPENDICES

Appendix A: Participant Consent Form

Appendix B: 36-Question Medical Outcomes Survey Short-Form General Health Survey

Appendix C: SF-36 Measurement Model

Appendix D: ISMI

Appendix E: PHQ-15

Appendix F: Narrative Therapy Curriculum Examples

Appendix G: Sample Size Calculation:
Appendix A: Participant Consent Form

COMPOUND AUTHORIZATION AND CONSENT FOR PARTICIPATION
IN A RESEARCH STUDY
YALE UNIVERSITY

Study Title: Narrative Therapy and Quality Of Life in Functional Neurological Disorder

Principal Investigator (the person who is responsible for this research):
Amber Locklear Wilder, 100 Church Street South, Suite A250, New Haven, CT 06519

Research Study Summary:
- We are asking you to join a research study.
- The purpose of this research study is to compare the effect of two psychotherapy regimens on quality of life, physical symptoms, and internalized stigma in people with Functional Neurological Disorder.
- Study activities will include attending 12 weekly 1-hour individual psychotherapy sessions with a licensed therapist. Some participants will be assigned to also attend 12 weekly 1-hour group therapy session, which involves personal story writing. Participants will complete questionnaires at three points throughout the study.
- Your involvement will require 12-24 hours over 16 weeks.
- There may be some risks from participating in this study. We do not expect serious adverse events, but engaging in psychotherapy can cause emotional distress when remembering or talking about difficult or traumatic experiences. You can choose to leave the study or therapy sessions at any time without consequences or repercussions.
- The study may have benefits to you. This study involves psychotherapy designed to support participants in processing emotions and building coping skills, which are associated with improved mood and social functioning.
- Taking part in this study is your choice. You can choose to take part, or you can choose not to take part in this study. You also can change your mind at any time. Whatever choice you make will not have any effect on your relationship with Yale New Haven Health System.
- If you are interested in learning more about the study, please continue reading, or have someone read to you, the rest of this document. Ask the study staff questions about anything you do not understand. Once you understand the study, we will ask you if you wish to participate; if so, you will have to sign this form.

Why is this study being offered to me?
We are asking you to take part in a research study because you are an adult with a diagnosis of Functional Neurological Disorder who is receiving treatment at a Yale New Haven Health System location. We are looking for 94 participants to be part of this research study.

What is the study about?
The purpose of this study is to evaluate if narrative therapy is associated with improved health-related quality of life when used alongside the standard

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treatment of cognitive behavioral therapy for people with Functional Neurological Disorder.

What are you asking me to do and how long will it take?
If you agree to take part, your participation in this study will involve 12 weeks of 1 or 2 weekly therapy sessions lasting 1 hour each. We think that the study will take 12-24 hours of your time depending on your group assignment. You will first meet with a neurologist to confirm your diagnosis by physical exam and review of your medical records. At that time, a research team member will assist you in completing 4 electronic questionnaires. Next, you will be randomly assigned to a treatment group. One group will attend weekly 1-hour individual cognitive behavioral therapy sessions by video or in-person for 12 sessions over a period of 16 weeks. The other group will also attend weekly 1-hour individual cognitive behavioral therapy sessions by video or in-person for 12 sessions over a period of 16 weeks, with additional weekly 1-hour group narrative therapy sessions for 12 weeks. You will be asked to complete 3 electronic questionnaires at the end of your treatment and again 6 months later. We will contact you by telephone before the 6-month follow-up. You will continue your current medical and psychiatric care outside of this study.

Questionnaires will include:
Personal demographic information such as your age, sex, race, income, and education history.
Questions about any physical symptoms you experience, such as pain or nausea.
Questions about your agreement or disagreement with specific statements on mental illness.
Questions about your perspectives of your own mental and physical health.

Are there any risks from participating in this research?
If you decide to take part in this study, you may experience emotional distress due to remembering or discussing upsetting or traumatic experiences during therapy sessions. You may leave the study or therapy sessions at any time without consequences or repercussions.
There is the possible risk of loss of confidentiality, but your private health information will be stored separately from any personal identifiers.
We do not expect any physical risks from taking part in this study.

How can the study possibly benefit me or others?
You may benefit from taking part in this study due to improved mental or physical health outcomes resulting from psychotherapy.
We hope that our results will add to the knowledge about Functional Neurological Disorder treatment.

Are there any costs to participation?
You will not have to pay for taking part in this study. The only costs may include transportation and your time coming to the study visits.

Will I be paid for participation?
You will not be paid for taking part in this study.

How will you keep my data safe and private?
All of your responses will be held in confidence. Only the researchers involved in this study and those responsible for research oversight (such as representatives of the Yale University Human Research Protection Program, the Yale University Institutional Review Boards, and others) will have access to any information that could identify you that you provide. We will share it with others if you agree to it or when we have to do it because U.S. or State law requires it. For example, we will tell somebody if we learn that you are hurting a child or an older person.

Any paper documents containing your personal information will be stored in a locked cabinet on YNHHS property and will only be accessible to necessary research personnel. Your electronic data will be coded using a unique participant number in place of any identifying information, then encrypted on a password-protected secure server only accessible to necessary research personnel. When we publish the results of the research or talk about it in conferences, we will not use your name. If we want to use your name, we would ask you for your permission.

We will also share information about you with other researchers for future research but we will not use your name or other identifiers. We will not ask you for any additional permission.

**What Information Will You Collect About Me in this Study?**
The information we are asking to use and share is called “Protected Health Information.” It is protected by a federal law called the Privacy Rule of the Health Insurance Portability and Accountability Act (HIPAA). In general, we cannot use or share your health information for research without your permission. If you want, we can give you more information about the Privacy Rule. Also, if you have any questions about the Privacy Rule and your rights, you can speak to Yale Privacy Officer at 203-432-5919.

The specific information about you and your health that we will collect, use, and share includes:
- Research study records
- Medical and laboratory records of only those services provided in connection with this Study.
- The entire research record and any medical records held by Yale New Haven Health System created from: 01/01/1900 to: 12/31/2025
- Records about phone calls made as part of this research
- Records about your study visits
- Information obtained during this research regarding
  - Physical exams
  - Questionnaires
  - The diagnosis and treatment of a mental health condition
  - Use of illegal drugs or the study of illegal behavior

**How will you use and share my information?**
We will use your information to conduct the study described in this consent form. We may share your information with:
- The U.S. Department of Health and Human Services (DHHS) agencies
- Representatives from Yale University, the Yale Human Research Protection Program and the Institutional Review Board (the committee that reviews, approves, and monitors research on human participants), who are responsible for ensuring research compliance. These individuals are required to keep all information confidential.
• Health care providers who provide services to you in connection with this study.
• Principal Investigator of the study
• Co-Investigators and other investigators
• Study Coordinator and Members of the Research Team
• Data and Safety Monitoring Boards and others authorized to monitor the conduct of the Study

We will do our best to make sure your information stays private. But, if we share information with people who do not have to follow the Privacy Rule, your information will no longer be protected by the Privacy Rule. Let us know if you have questions about this. However, to better protect your health information, agreements are in place with these individuals and/or companies that require that they keep your information confidential.

**Why must I sign this document?**

By signing this form, you will allow researchers to use and disclose your information described above for this research study. This is to ensure that the information related to this research is available to all parties who may need it for research purposes. You always have the right to review and copy your health information in your medical record.

**What if I change my mind?**

The authorization to use and disclose your health information collected during your participation in this study will never expire. However, you may withdraw or take away your permission at any time. You may withdraw your permission by telling the study staff or by writing to Amber Locklear Wilder 100 Church Street South, Suite A250, New Haven, CT 06519

If you withdraw your permission, you will not be able to stay in this study but the care you get from your doctor outside this study will not change. No new health information identifying you will be gathered after the date you withdraw. Information that has already been collected may still be used and given to others until the end of the research study to ensure the integrity of the study and/or study oversight.

**What if I want to refuse or end participation before the study is over?**

Taking part in this study is your choice. You can choose to take part, or you can choose not to take part in this study. You also can change your mind at any time. Whatever choice you make will not have any effect on your relationship with Yale New Haven Health System.

**Who should I contact if I have questions?**

Please feel free to ask about anything you don't understand.

If you have questions later or if you have a research-related problem, you can call the Principal Investigator at 203-785-2860

If you have questions about your rights as a research participant, or you would like to speak with someone other than the Principal Investigator or study team to discuss problems, concerns, or questions, or to obtain information or offer suggestions, you can call the Yale Institutional Review Boards at (203) 785-4688 or email hrpp@yale.edu.

If you have questions about the Psychology Subject Pool, you may contact the coordinator at (203) 432-4518, or psychsubject.pool@yale.edu.
A description of this clinical trial will be available on http://www.ClinicalTrials.gov, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

**Authorization and Documentation of Consent**

Your signature below indicates that you read and understand this consent form and the information presented and that you agree to be in this study.

We will give you a copy of this form.

<table>
<thead>
<tr>
<th>Participant Printed Name</th>
<th>Participant Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Person Obtaining Consent Printed Name</th>
<th>Person Obtaining Consent Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix B: 36-Question Medical Outcomes Survey Short-Form General Health Survey

<table>
<thead>
<tr>
<th>Label</th>
<th>SF-36 QUESTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>GH1</td>
<td>1. In general, would you say your health is:</td>
</tr>
<tr>
<td>HT</td>
<td>2. Compared to one year ago, how would you rate your health in general now?</td>
</tr>
<tr>
<td></td>
<td>3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? Is so, how much?</td>
</tr>
<tr>
<td>PR1</td>
<td>a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports</td>
</tr>
<tr>
<td>PR2</td>
<td>b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf</td>
</tr>
<tr>
<td>PR3</td>
<td>c. Lifting or carrying groceries</td>
</tr>
<tr>
<td>PR4</td>
<td>d. Climbing several flights of stairs</td>
</tr>
<tr>
<td>PR5</td>
<td>e. Climbing one flight of stairs</td>
</tr>
<tr>
<td>PR6</td>
<td>f. Bending, kneeling, or stooping</td>
</tr>
<tr>
<td>PR7</td>
<td>g. Walking more than a mile</td>
</tr>
<tr>
<td>PR8</td>
<td>h. Walking several blocks</td>
</tr>
<tr>
<td>PR9</td>
<td>i. Walking one block</td>
</tr>
<tr>
<td>PR10</td>
<td>j. Bathing or dressing yourself</td>
</tr>
<tr>
<td>RP1</td>
<td>4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?</td>
</tr>
<tr>
<td>RP2</td>
<td>a. Cut down on the amount of time you spent on work or other activities</td>
</tr>
<tr>
<td>RP3</td>
<td>b. Accomplished less than you would like</td>
</tr>
<tr>
<td>RP4</td>
<td>c. Were limited in the kind of work or other activities</td>
</tr>
<tr>
<td>RP5</td>
<td>d. Had difficulty performing the work or other activities (for example, it took extra effort)</td>
</tr>
<tr>
<td>RE1</td>
<td>5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?</td>
</tr>
<tr>
<td>RE2</td>
<td>a. Cut down on the amount of time you spent on work or other activities</td>
</tr>
<tr>
<td>RE3</td>
<td>b. Accomplished less than you would like</td>
</tr>
<tr>
<td>SF1</td>
<td>c. Didn’t do work or other activities as carefully as usual</td>
</tr>
<tr>
<td>SF2</td>
<td>6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?</td>
</tr>
<tr>
<td>BP1</td>
<td>7. How much bodily pain have you had during the past 4 weeks?</td>
</tr>
<tr>
<td>BP2</td>
<td>8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?</td>
</tr>
<tr>
<td>VT1</td>
<td>9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks—</td>
</tr>
<tr>
<td>VT2</td>
<td>a. Did you feel full of pep?</td>
</tr>
<tr>
<td>MH1</td>
<td>b. Have you been a very nervous person?</td>
</tr>
<tr>
<td>MH2</td>
<td>c. Have you felt so down in the dumps that nothing could cheer you up?</td>
</tr>
<tr>
<td>MH3</td>
<td>d. Have you felt calm and peaceful?</td>
</tr>
<tr>
<td>VT3</td>
<td>e. Did you have a lot of energy?</td>
</tr>
<tr>
<td>MH4</td>
<td>f. Have you felt downhearted and blue?</td>
</tr>
<tr>
<td>VT4</td>
<td>g. Did you feel worn out?</td>
</tr>
<tr>
<td>MH5</td>
<td>h. Have you been a happy person?</td>
</tr>
<tr>
<td>SF3</td>
<td>i. Did you feel tired?</td>
</tr>
<tr>
<td>SF4</td>
<td>10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?</td>
</tr>
<tr>
<td>GH2</td>
<td>11. How TRUE or FALSE is each of the following statements for you?</td>
</tr>
<tr>
<td>GH3</td>
<td>a. I seem to get sick a little easier than other people</td>
</tr>
<tr>
<td>GH4</td>
<td>b. I am as healthy as anybody I know</td>
</tr>
<tr>
<td>GH5</td>
<td>c. I expect my health to get worse</td>
</tr>
<tr>
<td>GH6</td>
<td>d. My health is excellent</td>
</tr>
</tbody>
</table>

**SF-36 RESPONSE CHOICES**

1. Excellent, Very good, Good, Fair, Poor
2. Much better now than one year ago, Some what better now than one year ago, About the same as one year ago, Somewhat worse now than one year ago, Much worse now than one year ago
3. Yes, limited a lot; Yes, limited a little; No, not limited at all
4. & 5. Yes, No
6. Not at all, Slightly, Moderately, Quite a bit, Extremely
7. None, Very mild, Mild, Moderate, Severe, Very severe
8. Not at all, A little bit, Moderately, Quite a bit, Extremely
9. All of the time, Most of the time, A good bit of the time, Some of the time, A little of the time, None of the time
10. All of the time, Most of the time, Some of the time, A little of the time, None of the time
11. Definitely true, Mostly true, Don’t know, Mostly false, Definitely false

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Appendix C: SF-36 Measurement Model

Figure 3.1 illustrates the measurement model underlying the construction of SF-36 multi-item scales and summary measures. This model has three levels: (1) items, (2) scales that aggregate items, and (3) summary measures that aggregate scales. All but one of the 36 items (self-reported health transition) are used to score the eight SF-36 scales.

**FIGURE 3.1 SF-36 MEASUREMENT MODEL**

- **Items**
  - 3a. Vigorous Activities
  - 3b. Moderate Activities
  - 3c. Lift, Carry Groceries
  - 3d. Climb Several Flights
  - 3e. Climb One Flight
  - 5f. Bend, Kleen
  - 3g. Walk Miles
  - 3h. Walk Several Blocks
  - 3i. Walk One Block
  - 3j. Bathe, Dress
  - 4a. Cut Down Time
  - 4b. Accomplished Less
  - 4c. Limited in Kind
  - 4d. Had Difficulty
  - 7a. Pain-Magnitude
  - 6a. Pain-Interference
  - 1. EQVFP Rating
  - 11a. Sick Easier
  - 11b. As Healthy
  - 11c. Health To Get Worse
  - 11d. Health Excellent
  - 3a. Peptul
  - 9a. Energy
  - 9b. Warn Out
  - 9c. Tired
  - 6a. Social-Extent
  - 10a. Social-Time
  - 5a. Cut Down Time
  - 5b. Accomplished Less
  - 5d. Not Careful
  - 9a. Nervous
  - 9c. Down in Dumps
  - 9d. Peaceful
  - 9d. Blue/Sad
  - 9e. Happy

- **Scales**
  - Physical Functioning (PF)
  - Role-Physical (RP)
  - Physical Health
  - Bodily Pain (BP)
  - General Health (GH)*
  - Vitality (VT)*
  - Social Functioning (SF)*
  - Mental Health
  - Role-Emotional (RE)
  - Mental Health (MH)

* Significant correlation with other summary measure.
Appendix D: Internalized Stigma of Mental Illness Inventory (ISMI)

Internalized Stigma of Mental Illness Inventory (ISMI)

We are going to use the term "mental illness" in the rest of this questionnaire, but please think of it as whatever you feel is the best term for it. For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4).

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel out of place in the world because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Mentally ill people tend to be violent.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. People discriminate against me because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I avoid getting close to people who don’t have a mental illness to avoid rejection.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I am embarrassed or ashamed that I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Mentally ill people shouldn’t get married.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. People with mental illness make important contributions to society.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I feel inferior to others who don’t have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I don’t socialize as much as I used to because my mental illness might make me look or behave &quot;weird.&quot;</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. People with mental illness cannot live a good, rewarding life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I don’t talk about myself much because I don’t want to burden others with my mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Negative stereotypes about mental illness keep me isolated from the &quot;normal&quot; world.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. Being around people who don’t have a mental illness makes me feel out of place or inadequate.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. I feel comfortable being seen in public with an obviously mentally ill person.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. People often patronize me, or treat me like a child, just because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. I am disappointed in myself for having a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. Having a mental illness has spoiled my life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. People can tell that I have a mental illness by the way I look.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. Because I have a mental illness, I need others to make most decisions for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I stay away from social situations in order to protect my family or friends from embarrassment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. People without mental illness could not possibly understand me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. People ignore me or take me less seriously just because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. I can’t contribute anything to society because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. Living with mental illness has made me a tough survivor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. Nobody would be interested in getting close to me because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. In general, I am able to live my life the way I want to.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. I can have a good, fulfilling life, despite my mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28. Others think that I can’t achieve much in life because I have a mental illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29. Stereotypes about the mentally ill apply to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

J. Ritscher, University of California, San Francisco. ritscher@hpa.ucsf.edu
## Appendix E: Patient Health Questionnaire 15-Item Somatic Symptom Severity Scale

### Patient Health Questionnaire 15-Item Somatic Symptom Severity Scale

<table>
<thead>
<tr>
<th>During the past 4 weeks, how much have you been bothered by any of the following problems?</th>
<th>Not bothered at all</th>
<th>Bothered a little</th>
<th>Bothered a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Stomach pain</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>b. Back pain</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>c. Pain in your arms, legs, or joints (knees, hips, etc.)</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>d. Menstrual cramps or other problems with your periods [Women only]</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>e. Headaches</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>f. Chest pain</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>g. Dizziness</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>h. Fainting spells</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>i. Feeling your heart pound or race</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>j. Shortness of breath</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>k. Pain or problems during sexual intercourse</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>l. Constipation, loose bowels, or diarrhea</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>m. Nausea, gas, or indigestion</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>n. Feeling tired or having low energy</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>o. Trouble sleeping</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
Appendix F: Narrative Therapy Curriculum Examples

Step 1: Building Rapport
- Intake and understanding the problem

Step 2: Identifying the Internalized Story
- Discussing how the problem influenced the individual
- Creating a personal representation of the problem

Step 3: Finding Unique Outcomes
- Looking for gaps in the narrative
- Helping the client identify points in their lives when they were not succumbed by the problem

Step 4: Thicken the Alternative Story
- Exploring identified unique outcomes
- Asking Landscape of Identity questions, focusing on:
  - Values and beliefs
  - Meaning
  - Purpose and intention
- Asking Landscape of Action questions, focusing on:
  - Events
  - Plot
  - Re-membering
  - Identify specific people who are influential in the preferred identity
  - Trace the history of their values to those people

Step 5: Retelling the Narrative
- Weaving together the unique outcomes into the preferred narrative
- Drawing from internal resources, values, meaningful experiences, and significant people

---

Narrative Enhancement and Cognitive Therapy (NECT)

1. Introduction - 1 session
   - Overview of intervention, exercise asking participant to describe him/herself, his/her relationship with mental illness and his/her expectations from the intervention

2. Psychoeducation - 2 sessions
   - Information about stigma and self-stigma, common myths about self-stigma are presented and challenged with research data

3. Cognitive Restructuring - 4 sessions
   - Information on the connection between thoughts, emotions and behaviors and on the different types of negative thoughts
   - Strategies for challenging stigma-related and other negative thoughts
   - At-home practice exercises

4. Narrative Enhancement - 4 sessions
   - Story-telling exercises on recent life events or illness-related success stories
   - Guidelines for providing feedback are presented
   - Facilitators and participants listen to stories and provide feedback on coherence and themes
   - At-home practice exercises

5. Conclusion - 1 session
   - Exercise asking participant to describe him/herself, his/her relationship with mental illness
   - Summary of group accomplishments
Appendix G: Sample Size Calculation

### TABLE 5.4 SAMPLE SIZES NEEDED TO DETECT DIFFERENCES BETWEEN POST-INTERVENTION SCORES OF TWO EXPERIMENTAL GROUPS WITH PRE-INTERVENTION SCORES AS COVARIATES

<table>
<thead>
<tr>
<th>Number of Points Difference</th>
<th>1</th>
<th>2</th>
<th>5</th>
<th>10</th>
<th>20</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PCS</strong></td>
<td>801</td>
<td>201</td>
<td>33</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td><strong>MCS</strong></td>
<td>801</td>
<td>201</td>
<td>33</td>
<td>9</td>
<td>5</td>
</tr>
</tbody>
</table>

Note: Estimates assume alpha = 0.05, two-tailed test, power = 80% (Cohen, 1988), and an intertemporal correlation of .70.

<table>
<thead>
<tr>
<th>Group</th>
<th>Population Mean</th>
<th>Standard Deviation</th>
<th>N Per Group</th>
<th>Standard Error</th>
<th>95% Lower</th>
<th>95% Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raw Difference</td>
<td>5.0</td>
<td>10.0</td>
<td>64</td>
<td>1.77</td>
<td>1.51</td>
<td>8.49</td>
</tr>
</tbody>
</table>

Alpha = 0.050, Tail = 2

**Summary - Power**

For the given effect size (population mean difference of 5.0), SD (10.0), sample sizes (64 and 64), and alpha (0.050, 2-tailed), power is 0.801.

This means that 80% of studies would be expected to yield a significant effect, rejecting the null hypothesis that the two population means are equal.
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