

## An Online Educational Program for Individuals With Dissociative Disorders and Their Clinicians: 1-Year and 2-Year Follow-Up

Bethany L. Brand,<sup>1</sup> Hugo J. Schielke,<sup>2</sup> Karen T. Putnam,<sup>3</sup> Frank W. Putnam,<sup>3</sup> Richard J. Loewenstein,<sup>4</sup> Amie Myrick,<sup>5</sup> Ellen K. K. Jepsen,<sup>6</sup> Willemien Langeland,<sup>7</sup> Kathy Steele,<sup>8</sup> Catherine C. Classen,<sup>9</sup> and Ruth A. Lanius<sup>10</sup>

<sup>1</sup>Department of Psychology, Towson University, Towson, Maryland, USA

<sup>2</sup>California Department of State Hospitals, Napa, California, USA

<sup>3</sup>The Department of Psychiatry, University of North Carolina School of Medicine at Chapel Hill, Chapel Hill, North Carolina, USA

<sup>4</sup>Sheppard Pratt Health System and University of Maryland School of Medicine, Baltimore, Maryland, USA

<sup>5</sup>Family and Children's Services, Bel Air, Maryland

<sup>6</sup>Modum Bad Psychiatric Center, Vikersund, Norway

<sup>7</sup>Bascous, France

<sup>8</sup>Atlanta, Georgia

<sup>9</sup>University of California San Francisco and Zuckerberg San Francisco General Hospital, San Francisco, California, USA

<sup>10</sup>Western University, London, Ontario, Canada

Individuals with dissociative disorders (DDs) are underrecognized, underserved, and often severely psychiatrically ill, characterized by marked dissociative and posttraumatic stress disorder (PTSD) symptoms with significant disability. Patients with DD have high rates of nonsuicidal self-injury (NSSI) and suicide attempts. Despite this, there is a dearth of training about DDs. We report the outcome of a web-based psychoeducational intervention for an international sample of 111 patients diagnosed with dissociative identity disorder (DID) or other complex DDs. The Treatment of Patients with Dissociative Disorders Network (TOP DD Network) program was designed to investigate whether, over the course of a web-based psychoeducational program, DD patients would exhibit improved functioning and decreased symptoms, including among patients typically excluded from treatment studies for safety reasons. Using video, written, and behavioral practice exercises, the TOP DD Network program provided therapists and patients with education about DDs as well as skills for improving emotion regulation, managing safety issues, and decreasing symptoms. Participation was associated with reductions in dissociation and PTSD symptoms, improved emotion regulation, and higher adaptive capacities, with overall sample  $|d|s = 0.44\text{--}0.90$ , as well as reduced NSSI. The improvements in NSSI among the most self-injurious patients were particularly striking. Although all patient groups showed significant improvements, individuals with higher levels of dissociation demonstrated greater and faster improvement compared to those lower in dissociation  $|d|s = 0.54\text{--}1.04$  vs.  $|d|s = 0.24\text{--}0.75$ , respectively. These findings support dissemination of DD treatment training and initiation of treatment studies with randomized controlled designs.

Dissociative disorders (DDs) have a reported lifetime prevalence of 9–18% in international general population studies,

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Correspondence concerning this article should be addressed to Dr. Bethany Brand, Towson University, Psychology Department, Towson, Maryland, 21252. E-mail: bbrand@towson.edu

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with the most severe DD, dissociative identity disorder (DID), present in approximately 1–1.5% of the general population (Şar, 2011). Dissociative disorders are common in inpatient, day treatment, outpatient, emergency department, and substance abuse treatment populations (Loewenstein, Frewen, & Lewis-Fernández, 2017; Şar, 2011). Nonetheless, DDs remain underdiagnosed and undertreated. For example, in a sample of patients from an urban clinic in the United States, only 16.7% of patients who were found to meet criteria for a DD carried a DD diagnosis (Foote, Smolin, Kaplan, Legatt, & Lipschitz, 2006). As a result of this underdiagnosis, DID patients spend an average of 5–12.4 years receiving mental health treatment before they are diagnosed with DID (Spiegel et al., 2011).

Typically, DID in particular is characterized by a complex symptom picture and high degree of functional impairment; it

is also associated with higher rates of childhood trauma than any other diagnostic group (Spiegel et al., 2011). Patients with DD have high rates of comorbid posttraumatic stress disorder (PTSD), major depressive disorder, somatic symptom disorder, and substance use disorders as well as high rates of nonsuicidal self-injury (NSSI) and suicide attempts (Foote, Smolin, Neft, & Lipschitz, 2008; Webermann, Myrick, Taylor, Chasson, & Brand, 2015). Patients with DD also have higher rates of suicide attempts than individuals with borderline personality disorder, PTSD, or substance abuse disorders but do not have a comorbid DD (Foote et al., 2008). Dissociative disorders are also associated with a high level of impairment. For example, in a representative sample of New York citizens, DD patients' average impairment scores were 50% higher than those of patients with other psychiatric disorders, with DID individuals demonstrating the highest level of impairment (Johnson, Cohen, Kasena, & Brook, 2006). The severity and chronicity of DD patients' symptoms usually necessitate frequent treatment at more restrictive levels of care (Mueller-Pfeiffer et al., 2012), which is associated with significant health care costs.

However, effective treatment for DDs has been shown to reduce patient suffering and health care costs (Brand et al., 2013; Lloyd, 2016; Myrick, Webermann, Langeland, Putnam, & Brand, 2017). Meta-analyses of eight open trials of DD treatment yielded an average effect size of  $d = 0.71$  for decreased dissociation, anxiety, depression, somatoform symptoms, substance use, and general distress (Brand, Classen, McNary, & Zaveri, 2009). A study of DD patients found cross-sectional and longitudinal reductions in inpatient and outpatient costs, as reported by patients and therapists, which suggests that DD treatment may be associated with reduced costs over time (Myrick et al., 2017).

A prospective, longitudinal study of 280 DD patients and 292 clinicians from six continents found that, over the course of 30 months of individual treatment, patients showed significant decreases in depression, PTSD, distress, dissociation, suicide attempts, NSSI, hospitalizations, drug use, physical pain, and treatment costs (Brand, Classen, Lanius et al., 2009; Brand et al., 2013; Myrick et al., 2017). A Norwegian inpatient study (Jepsen, Langeland, Sexton & Heir, 2014) discovered that for DD patients, a generic trauma-focused treatment without attention to dissociation failed to reduce amnesia or dissociative identity alteration although depression and general psychiatric symptoms improved. Jepsen and colleagues (2014) concluded that unless a dissociation-specific treatment is provided, dissociative symptoms associated with DDs are unlikely to improve. Studies of individuals with PTSD, both with and without borderline personality disorder, have found that higher dissociation levels predict poor response to standard treatments, such as eye movement desensitization and reprocessing (EMDR) and dialectical behavior therapy (DBT; Bae, Kim, & Park, 2016; Kleindienst et al., 2011). Despite these data, most psychiatric and psychology textbooks fail to present empirical research about DDs, or they provide inaccurate or sensationalized information about diagnosis and treatment of DDs (Loewenstein

et al., 2017; Wilgus, Packer, Lile-King, Miller-Perrin, & Brand, 2016).

Expert consensus treatment guidelines are available for DID in children and adults (International Society for the Study of Trauma and Dissociation [ISSTD], 2004, 2011). These guidelines recommend a phasic treatment model that, consistent with a survey of international DD experts (Brand et al., 2012), emphasizes patient safety and stabilization. Due to the severity and complexity of DD symptoms and impairment, the first stage explicitly focuses on safety and stabilization; DD patients often decompensate if there is a premature attempt to process traumatic memories before behavioral stabilization and acquisition of emotion and symptom management skills (ISSTD et al., 2011). The symptoms of these chronic complex DDs have been conceptualized as reflective of emotional dysregulation related to trauma (Brand & Lanius, 2014), and emotional dysregulation and posttraumatic stress have been found to predict increased dissociation and tension reduction actions (Briere, Hodges, & Godbout, 2010). Conceptualizing NSSI and suicidal behaviors as attempts at self-regulation, Stage 1 treatment is recommended to utilize a multimodal, present-centered approach that emphasizes psychoeducation and cognitive-behavioral interventions while conceptualizing relationship dynamics through psychodynamic and attachment theories (Brand, 2001). Patients are taught healthy coping skills to manage dysregulation, including grounding to reduce dissociation; emotion regulation skills to replace reliance on unhealthy behaviors (e.g., NSSI, substance abuse) to reduce overwhelming emotions; containment of intrusive PTSD symptoms; and methods for managing unsafe behaviors. When patients demonstrate improved awareness and tolerance of emotions, decreased dissociation, mastery of basic symptom management skills, and improved safety, they may (optionally) progress to Stage 2, which adds carefully paced processing of trauma memories. A survey of 36 international experts (Brand et al., 2012) indicated that experts remain attentive to safety and stability until the third phase of treatment. In Stage 3, patients are able to devote more energy to increasing social and occupational activities and may completely or partially integrate self-states (Loewenstein et al., 2017).

Despite these guidelines, accessing specialized trauma treatment can be difficult or impossible for many patients with DDs, partially due to the fact that few clinicians report having any training in the diagnosis and treatment of dissociation and DDs (Brand et al., 2014, 2016). Internet-based interventions, by contrast, are easy to access (Bolton & Dorstyn, 2015; Litz, Engel, Bryant, & Papa, 2007), and Internet-based interventions aimed at treating symptoms of depression, anxiety, and PTSD have been associated with medium-to-large effect sizes (Bolton & Dorstyn, 2015). Unfortunately, DD patients are typically excluded from most Internet- and non-Internet-based PTSD treatment studies due to typical exclusion criteria, including high dissociation scores, active substance abuse, NSSI, suicidality, psychosis, lack of social support, and/or high levels of stressors, among others (Bolton & Dorstyn, 2015; Klein et al., 2010; Knaevelsrud & Maercker,

2007; Litz et al., 2007). Internet-based DD-focused interventions have not yet been investigated; however, in a study of Internet-based cognitive behavior therapy (CBT) interventions for PTSD that excluded highly dissociative individuals, the authors did find that dissociation scores significantly decreased during the intervention (Klein et al., 2010).

For the present study, we designed an Internet-based program for early-stage DD patients and their therapists that focused on stabilization, safety, and management of DD and PTSD symptoms in an effort to determine whether psychoeducation consistent with ISSTD treatment guidelines and expert recommendations would be associated with decreased symptoms and improved functioning. The TOP DD Network program's psychoeducational intervention is an online, password-protected program consisting of 45 short (i.e., 5–15-min) educational videos, 40 of which are paired with structured writing and behavioral practice exercises that assist patients in cognitively and behaviorally applying the video's educational content. In this report, we present 2-year outcomes, including changes in adaptive capacities, emotion regulation, PTSD and dissociative symptoms, NSSI, suicide attempts, and hospitalizations.

## Method

### Participants

Patient-therapist dyads were recruited through announcements on mental health professional listservs and by contacting therapists who had participated in the naturalistic TOP DD study. Interested therapists were instructed to invite one patient who had been diagnosed with DID, DD not otherwise specified (DDNOS), or other specified DD (OSDD) to participate in the study. The DDNOS diagnosis is specific to the fourth edition (text revision) of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR*; American Psychiatric Association [APA], 2000), and the OSDD is specific to the fifth edition of the *DSM (DSM-5*; APA, 2013). At the time of the study, clinicians were still shifting from *DSM-IV-TR* to *DSM-5*; thus, either clinical diagnosis was permitted. Patient exclusion criteria were as follows: being younger than 18 years of age, unable to read English, and/or not having access to the Internet. Therapist exclusion criteria were: not having an interested/eligible patient, not being able to read English, and/or not having Internet access. We did not exclude patients with comorbid disorders, current suicidality, NSSI, substance abuse, psychosocial stressors, instability, or isolation. Participants were not compensated. As this study is still in progress, dyads included in the presented analyses ( $N = 111$ ) are a subset of those who will be ultimately enrolled. Participants were included in these analyses if they completed a baseline survey and a progress survey at either the 12-month or 24-month time points. We compared baseline data of individuals who were not included in the presented analyses with those included and found no differences in demographics or measures at entry into the program. Participants in this international sample were mostly female (88.3%) and Caucasian

(86.5%); see Table 1 and Supplementary Table S1 for additional patient demographic information.

Therapists and patients accessed password-protected websites to complete informed consents and surveys and access educational videos, journaling, and behavioral practice exercises. Surveys were identified by code numbers. The study received Institutional Review Board approval from Towson University (Towson, MD). The consent materials explained that participant pairs could discontinue at any time, but if the therapist discontinued, the patient would be unenrolled to ensure sufficient patient support during the intervention.

### Procedure

Therapists and patients completed a screening survey; if both members met inclusion criteria, they were emailed a URL to an initial survey (baseline), followed by an e-mail that provided access to the psychoeducational program and links to surveys every 6 months for 2 years. The educational materials were developed based on the research team's decades of experience working with DD patients in inpatient and outpatient settings, drawing on the results of a survey of experts (Brand et al., 2012), the ISSTD treatment guidelines, and findings that DD therapists and their patients could benefit from increased emphasis on trauma symptom management techniques (e.g., Myrick, Chasson, Lanius, Leventhal, & Brand, 2015). See the online Supplementary Materials for additional information regarding the theoretical and empirical foundations of the program's content.

A team of three authors (Brand, Schielke, & Lanius) wrote the video transcripts and outlined the journaling and behavioral exercises. These were then reviewed by members of the TOP DD team and DD patient and consumer advocates involved in public educational efforts. None of the patient or consumer reviewers were in treatment with research team members. The 45 final 5–15-min videos were filmed with the first author as spokesperson. Participants could watch the videos, read the video transcripts, and access the exercises as often as they found useful. To allow patients time to make meaningful use of the journaling and behavioral exercises, access to the next set of materials was delayed 1 week from the time of accessing the previous week's materials. Although patients and their therapists were required to participate together in the TOP DD program, we suggested that participants watch the videos and complete assignments outside of therapy to protect session time for individualized work.

The psychoeducational materials addressed the impact of trauma, including symptoms of PTSD, complex trauma reactions, and DDs; symptom and emotion management techniques; and the nature and functions of NSSI, suicidal, and risky behaviors (henceforth referred to collectively as "unsafe" or "unhealthy" behaviors) among traumatized people. We emphasized that although unsafe behaviors frequently represent attempts to self-regulate painful affects and intrusive memories, they fail to resolve the underlying emotional and trauma-based

Table 1  
Patient Demographics and Characteristics at Intake

Variable	High DES Group		Low DES Group		$t^a$	$df$
	$M$	$SD$	$M$	$SD$		
Age at intake (years)	43.1	9.73	41.98	11.23	0.55	108
	%	$n$	%	$n$	$\chi^2a$	$df$
Gender						
Female	89.0	63	87.5	35	0.73	2
Male	9.9	7	12.0	5		
Transgender	1.4	1	0.0	0		
Race/ethnicity						
Caucasian	83.1	59	92.5	37	0.23	4
Latino or Hispanic	5.6	4	0.0	0		
Asian	2.8	2	0.0	0		
Black	1.4	1	2.5	1		
Other	7.0	5	5.0	2		
Treatment stage						
Stabilization and safety	39.4	28	32.5	13	5.70	4
Between safety and processing	47.9	34	50.0	20		
Processing trauma	12.7	9	10.0	4		
Between processing trauma and reconnection	0.0	0	5.0	2		
Reconnection and integration	0.0	0	2.5	1		
DD diagnosis <sup>b</sup>						
DID ( <i>DSM-IV-TR</i> , <i>DSM-5</i> )	76.5	52	53.9	21	6.23	3
DDNOS ( <i>DSM-IV-TR</i> )	20.6	14	41.0	16		
OSDD ( <i>DSM-5</i> )	2.9	2	5.0	2		

Note. DES = Dissociative Experiences Scale; DID = dissociative identity disorder; DDNOS = dissociative disorder not otherwise specified; OSDD = other specified dissociative disorder; *DSM-IV-TR* = *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.); *DSM-5* = *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.).

<sup>a</sup> $t$  or chi-square tests used to examine differences between groups. <sup>b</sup>Diagnosis data missing for four participants (high DES group,  $n = 3$ ; low DES group,  $n = 1$ ).

symptoms that perpetuate their distress. Throughout the program, self-compassion and acceptance of emotions were emphasized, and, for DID patients, healthy collaboration among self-states (note that the *DSM-5* uses the term “personality states.” We prefer the term “self-states” as more conceptually and clinically accurate in terms of DID phenomenology and subjective experience). The content of the program is elaborated in the Supplementary Materials.

## Measures

**Dissociative experiences.** The Dissociative Experiences Scale II (DES; Carlson & Putnam, 1993) is a 28-item self-report measure of dissociative experiences. Each item presents 11 Likert scale response options ranging from 0% (*never*) to 100% (*always*). Higher average scores indicate a higher level of dissociation, with a possible score of 0 to 100. The DES cut point of 30 or above is based on a receiver operating characteristic (ROC) curve of 1,051 subjects in nine psychiatric disorder categories from seven centers (Carlson et al., 1993). Discriminant analysis has indicated that using a cutoff

score of 30 screens for DID with 76% sensitivity and specificity, and 85% specificity in a more representative subsample (Carlson et al., 1993). The DES has demonstrated good internal consistency (mean Cronbach’s  $\alpha$  across 16 studies = .93) and convergent validity ( $r = .67$  overall; see paper for methodology comparing  $r$ s with 8 different measures across 26 studies), and test–retest reliability ranging from .78 to .93 over 4–8 weeks (6 studies; van IJzendoorn & Schuengel, 1996). In this study, Cronbach’s alpha was .96 at each time point.

**Emotion regulation.** The Difficulties in Emotion Regulation Scale (DERS; Gratz & Roemer, 2004) is a 36-item self-report measure of nonacceptance of emotional responses, difficulties engaging in goal-directed behavior, impulse control difficulties, lack of emotional awareness, limited access to emotion regulation strategies, and lack of emotional clarity. Items are rated on a 5-point Likert scale of 1 (*almost never, 0–10%*) to 5 (*almost always, 91–100%*); scores can range from 36 to 180, with higher scores indicating greater dysregulation. The DERS has demonstrated good internal consistency (Cronbach’s  $\alpha = .93$ ) and test–retest reliability ( $\rho I = .88, p < .01$ ) and adequate

subscale test–retest reliability and well as construct and predictive validity (Gratz & Roemer, 2004). Cronbach's alpha values ranged from .94 to .96 in the current sample.

**Posttraumatic stress symptoms.** The Posttraumatic Stress Checklist—Civilian Form (PCL-C; Weathers, Litz, Huska, & Keane, 1994) is a 17-item self-report measure of *DSM-IV-TR* PTSD symptoms in the past month. Items are rated on a 5-point Likert scale that ranges from 1 (*not at all*) to 5 (*extremely*). Scores can range from 17 to 85; higher scores indicate a higher level of distress (Weathers & Ford, 1996). The PCL-C has demonstrated high overall diagnostic efficiency (90%; Blanchard, Jones-Alexander, Buckley, & Forneris, 1996) and strong test–retest reliability (.96 in a 2–3 day interval; Weathers et al., 1994). Cronbach's alpha values ranged from .88 to .92 in the current sample.

**Treatment progress.** The Progress in Treatment Questionnaire, patient version (PITQ-p; Schielke, Brand, & Marsic, 2017) is a self-report measure that assesses ability to manage emotions, symptoms, relationships, safety, and well-being over the prior 7 days. The PITQ-p consists of 32 expert-identified items, 6 of which (items 27–32) are only completed by patients who report experiencing dissociative self-states (DSS). Responses are rated on an 11-point Likert scale with options ranging from 0% (*never true*) to 100% (*always true*). Responses are added and then averaged (using either 26 or 32 items, depending on whether the patient has DSS). Possible scores range from 0 to 100; higher scores indicate better adaptive functioning. The PITQ-p has demonstrated evidence of good internal consistency (Cronbach's  $\alpha = .92$ ) and adequate convergent validity with measures of emotion-related functioning (DERS;  $r = -.67$ ), PTSD (PCL-C;  $r = -.47$ ), and dissociation (DES;  $r = -.42$ ), as well as correlations in expected directions with NSSI ( $r = -.34$ ) and psychological ( $r = .64$ ) and social ( $r = .28$ ) quality of life (Schielke et al., 2017). In the current sample, Cronbach's alpha values ranged from .92 to .96 for patients with DSS and from .91 to .96 for patients without DSS.

The Progress in Treatment Questionnaire, therapist version (PITQ-t; Schielke et al., 2017) is a therapist-completed measure of dissociative patients' ability to manage emotions, symptoms, relationships, safety, and well-being over the prior 6 months. The 29-item instrument assesses the percentage of time patients have demonstrated expert-identified adaptive behaviors and includes 6 items (items 24–29) that the therapist completes only for their patients with DSS. Responses are rated on an 11-point Likert scale with options ranging from 0% (*never*) to 100% (*always*), with higher average scores indicative of better adaptive functioning; possible scores range from 0 to 100. The PITQ-t has demonstrated good internal consistency (Cronbach's  $\alpha = .91$ ) and adequate convergent validity with measures of emotion-related functioning (DERS;  $r = -.35$ ), PTSD (PCL-C;  $r = -.41$ ), and dissociation (DES;  $r = -.29$ ), as well as correlations in expected directions with NSSI

( $r = -.37$ ) and psychological ( $r = .45$ ) and social ( $r = .22$ ) quality of life (Schielke et al., 2017). In the current sample, Cronbach's alpha values ranged from .92 to .95 for patients with DSS and from .89 to .94 for patients without DSS.

**Clinical data.** Therapists reported on patients' demographics, DD diagnosis, and stage of treatment. They also indicated the level of NSSI, suicide attempts, and hospitalizations over the prior 6 months.

## Data Analysis

Based on prior research that has indicated differences in therapeutic response related to severity of dissociation (e.g., Bae et al., 2016), we divided the sample into low dissociation (DES scores less than 30;  $n = 40$ ) and high dissociation (DES scores of 30 or more;  $n = 71$ ) groups using the ROC-derived cut point of 30 (Carlson et al., 1993). We calculated distributions and descriptive statistics; when normality was violated, dependent variables were analyzed with nonparametric methods.

The data were analyzed in two tiers. First, Cohen's  $d$  effect sizes were calculated using paired data to examine change in the observed variables post- and midintervention. Confidence intervals accounting for correlated paired data were constructed, and Cohen's (1988) traditional cut points were used to interpret the effect sizes as small (0.20), medium (0.50), or large (0.80).

We then ran a series of mixed models using SAS (Version 9.3). First, we examined whether time involved in the study was a significant predictor of change in the observed variables. Next, a series of  $2 \times 3$  repeated measures models examined the linear within-subject effects over time and the between-subject effects of the high and low DES groups. Smaller Akaike information criterion (AIC) and  $-2 \log$ -likelihood values indicated that an unstructured covariance matrix demonstrated the best model fit. Clinically relevant covariates (including female/male gender, age, native English-speaking country, how long the subject had been diagnosed with a DD, and treatment stage) were then included to evaluate how much variance they accounted for in the dependent variable, and significant covariates were included in the final models (countries in the native English-speaking category included the United States, Canada, United Kingdom, Australia and New Zealand. Non-English native language countries included Belgium, Israel, Norway, Spain, Sweden, and India). It should be noted that the SAS MIXED procedure accommodates missing data. Mixed models apply an iterative estimation of the restricted or residual maximum likelihood (REML) method instead of the basic least-squares method of general linear models. The REML method utilizes all available data and estimates the parameter for each subject. Bonferroni post hoc comparisons were constructed for significant interactions and main effects. Additional information on the overall sample, effect sizes, and model analyses can be found in the online Supplementary Materials.

Table 2  
Means and Standard Deviations for Continuous Outcome Measures: High and Low Dissociation (DES) Groups

Reporter and Scale	High Dissociation						Low Dissociation					
	Baseline ( <i>n</i> = 71)		Year 1 ( <i>n</i> = 50)		Year 2 ( <i>n</i> = 51)		Baseline ( <i>n</i> = 40)		Year 1 ( <i>n</i> = 26)		Year 2 ( <i>n</i> = 27)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Patient												
PITQ-p	41.54	14.56	49.15	15.69	58.57	19.53	51.24	11.43	55.28	17.43	62.40	13.40
DERS	125.66	21.69	113.16	23.86	100.04	26.34	107.35	16.11	104.46	20.65	91.15	19.29
PCL-C	65.42	8.97	59.46	10.55	54.14	13.37	52.60	9.56	50.12	13.67	47.15	12.14
DES	50.89	14.31	44.50	18.64	37.82	18.36	18.21	7.57	18.34	13.42	15.67	7.32
Therapist												
PITQ-t	48.39	12.49	53.53	13.48	54.77	14.07	53.64	12.48	57.37	14.62	59.15	17.29

Note. DES = Dissociative Experiences Scale; PCL-C = Posttraumatic Stress Checklist–Civilian; DERS = Difficulties in Emotion Regulation Scale; PITQ-p = Progress in Treatment Questionnaire–patient; PITQ-t = Progress in Treatment Questionnaire–therapist.

## Results

Patient demographics and characteristics at intake are presented in Table 1. Table 2 provides the means and standard deviations for the low and high dissociation groups at baseline, Year 1, and Year 2. Table 3 reports the postintervention (Year 2) and midintervention (Year 1) effect sizes for the overall sample and both DES groups and demonstrates postintervention improvements in each group on each measure. Supplementary Table S4 contains the parsimonious model summaries for significant main effects, covariates, and Time  $\times$  DES group interactions.

### Changes in Adaptive Capacities, Emotion Regulation, and Symptoms

At study completion, overall sample effect sizes indicated large improvements in adaptive capacities (as indicated by PITQ-p scores;  $|d| = 0.86$ ), and emotion regulation (as indicated by DERS scores;  $d = 0.90$ ); medium improvements in PTSD symptoms (as indicated by PCL-C scores;  $d = 0.65$ ); and slightly smaller improvements in dissociation (as indicated by DES scores;  $d = 0.48$ ). The high dissociation group demonstrated the greatest improvements, with large improvements in adaptive capacities ( $|d| = 0.94$ ), emotion regulation ( $d = 1.04$ ), PTSD symptoms ( $d = 0.93$ ), and dissociation ( $d = 0.81$ ). The low DES group demonstrated medium-approaching-strong improvements in postintervention adaptive capacities ( $|d| = 0.75$ ) and emotion regulation ( $d = .74$ ), and small improvements in PTSD symptoms ( $d = 0.32$ ) and dissociation ( $d = 0.24$ ).

At the study's halfway mark, overall sample effect sizes indicated small improvements in adaptive capacities ( $|d| = 0.47$ ), emotion regulation ( $d = 0.36$ ), PTSD symptoms ( $d = 0.41$ ), and dissociation ( $d = 0.22$ ). The high dissociation group again demonstrated the greatest improvements, with medium

improvements in adaptive capacities ( $|d| = 0.53$ ), emotion regulation ( $d = 0.54$ ), and PTSD symptoms ( $d = 0.61$ ), and the strongest improvements in dissociation of the three groups at this time point ( $d = 0.45$ ). The low DES group demonstrated small improvements in midintervention adaptive capacities ( $|d| = 0.39$ ), emotion regulation ( $d = 0.26$ ), and PTSD symptoms, ( $d = 0.20$ ). Dissociation was unchanged for the low DES group midintervention ( $d = 0.08$ ).

### Therapist-Reported Adaptive Capacities

Therapist-reported adaptive capacities (as measured using the PITQ-t) increased in the overall sample and both groups at Year 2 compared to baseline, with a medium effect size for the high DES group ( $|d| = 0.54$ ) and small effect sizes for the overall and low DES groups ( $|d|$ s = 0.44 and 0.30, respectively). There were no DES group main effects, only time effects,  $F(2, 102) = 10.56, p < .001$ . Bonferroni post hoc comparisons showed improvements for the overall group from baseline to Year 1,  $p = .003$ , and Year 2,  $p < .001$ . Finally, therapist ratings of patients' adaptive capacities covaried with treatment stage,  $F(1, 102) = 5.66, p = .019$ .

### Interactions, Covariates, and Post Hoc Comparisons for Patient Ratings

We identified interactions between DES group and time in relation to the DERS,  $F(2, 107) = 3.95, p = .022$ , and PCL-C,  $F(2, 104) = 4.10, p = .019$ . The high DES group demonstrated higher DERS and PCL-C scores at baseline and steeper reduction slopes compared to the low DES group.

Years diagnosed with a DD was weakly associated with PCL-C reductions,  $F(1, 104) = 3.98, p = .049$ , with lower scores found among those who had been diagnosed longer. Scores on the DERS covaried with gender,  $F(1, 107) = 5.86, p = .017$ , as did PITQ-p scores,  $F(1, 105) = 4.71, p = .032$ : Female

Table 3  
 Effect Size Comparisons and Patient Measures for the Overall Sample and High and Low Dissociation (DES) Groups

	Postintervention (Year 2)		Midintervention (Year 1)	
	<i>d</i>	95% CI	<i>d</i>	95% CI
PITQ-p <sup>a</sup>				
Overall sample	−0.86	[−1.10, −0.60]	−0.47	[−0.67, −0.27]
High DES group	−0.94	[−1.25, −0.62]	−0.53	[−0.77, −0.29]
Low DES group	−0.75	[−1.19, −0.31]	−0.39	[−0.77, 0.00]
DERS				
Overall sample	0.90	[0.65, 1.14]	0.36	[0.21, 0.62]
High DES group	1.04	[0.72, 1.36]	0.54	[0.23, 0.77]
Low DES group	0.74	[0.29, 1.18]	0.26	[−0.05, 0.56]
PCL-C				
Overall sample	0.65	[0.44, 0.86]	0.41	[0.21, 0.60]
High DES group	0.93	[0.62, 1.23]	0.61	[0.33, 0.89]
Low DES group	0.32	[0.02, 0.61]	0.20	[−0.16, 0.56]
DES				
Overall sample	0.48	[0.31, 0.65]	0.22	[0.07, 0.37]
High DES group	0.81	[0.53, 1.09]	0.45	[0.19, 0.70]
Low DES group	0.24	[−0.06, 0.53]	−0.08	[−0.46, 0.29]
PITQ-t <sup>a</sup>				
Overall sample	−0.44	[−0.77, −0.09]	−0.31	[−0.50, 0.−13]
High DES group	−0.54	[−0.80, −0.27]	−0.38	[−0.65, −0.10]
Low DES group	−0.30	[−0.72, 0.13]	−0.25	[−0.50, 0.01]

Notes. PITQ-p = Progress in Treatment Questionnaire–patient; DERS = Difficulties in Emotion Regulation Scale; PCL-C = Posttraumatic Stress Checklist–Civilian; DES = Dissociative Experiences Scale; PITQ-t = Progress in Treatment Questionnaire–therapist.

<sup>a</sup>Higher scores are better for the PITQ-t and PITQ-p; for these measures, a negative effect size reflects improvement.

participants demonstrated higher DERS scores ( $M = 121.20$  for female vs.  $M = 105.09$  for male participants) and lower PITQ-p scores ( $M = 43.82$  for female vs.  $M = 53.69$  for male patients) at baseline.

Main effect post hoc comparisons indicated differences between the high and low DES groups at all three time points; Bonferroni post hoc comparisons showed higher PCL-C scores for the high DES compared to the low DES group at baseline,  $p < .001$ ; Year 1,  $p < .001$ ; and Year 2,  $p = .026$ . The high DES group demonstrated significant improvement at post-2-year intervention,  $p < .001$ , and at the mid-1-year intervention,  $p < .001$ . Post hoc PITQ-p comparisons indicated that the low DES group had higher average scores ( $M = 56.49$ ) than the high DES group ( $M = 49.63$ ),  $p = .016$ . Patient-reported PITQ-p scores correlated with therapist-reported PITQ-t scores,  $r = .49$ ,  $p < .001$ .

### Changes in Safety and Hospitalization

In our sample, NSSI events were not normally distributed ( $M = 20.61$ ;  $SD = 37.08$ ;  $Mdn = 6$ ; range: 0–150). Therapist reports of patients' NSSI events in the past 6 months had maximum values of 150 events at baseline, decreasing to maximum counts of 10 at Years 1 and 2. For the 67 subjects with

reported NSSI events, therapists reported patients engaged in NSSI an average of 13.75 times in the 6 months prior to intake; this rate dropped to 1.96 times and 1.74 times by Years 1 and 2, respectively. More than half of the patients who engaged in NSSI (68.60%,  $n = 46$ ) decreased NSSI events over 2 years; 25.40% ( $n = 17$ ) reported an increase in NSSI from baseline. The remaining 6% ( $n = 4$ ) had no change in NSSI ( $n = 2$ ), increased then decreased ( $n = 1$ ), or decreased then increased ( $n = 1$ ) over the three time intervals. Wilcoxon signed rank tests examined the hypothesis that median differences between baseline to Year 1, Year 1 to Year 2, and baseline to Year 2 were equal for the high and low DES groups. The high DES group had a median count of two NSSI events at baseline and decreased at Year 1,  $z = 2.65$ ,  $p = .008$ , and Year 2,  $z = 4.00$ ,  $p < .001$ . The median number of NSSI events for the low DES group was 1. This decreased significantly by Year 1,  $z = 2.35$ ,  $p = .018$ . Year 2 reductions ( $z = 1.69$ ,  $p = .086$ ) did not meet the  $p < .05$  significance criteria. There were no differences in the high and low DES groups' NSSI between Years 1 and 2.

At study completion, patients' average number of suicide attempts in the prior 6 months was lower than at intake (intake  $M = 0.39$ ,  $SD = 1.54$  vs.  $M = 0.17$ ;  $SD = 0.80$  at year 2). Patients required an average of 22.27 days of hospitalization

in the 6 months prior to engaging in the study and 11.50 days of hospitalization 2 years later. Although the change in suicide attempts and days hospitalized were in the direction suggesting that the intervention was beneficial, they were not statistically significant.

### Discussion

This study examined the effectiveness of a web-based psychoeducation program designed to assist therapists of and patients with complex DDs, an underserved and severely symptomatic population. Participation in the TOP DD Network program was associated with reductions in dissociation and PTSD symptoms, improved emotion regulation, and higher adaptive capacities (i.e., PITQ scores). As indicated by effect size, the overall sample demonstrated large improvements in emotion regulation and patient-reported adaptive capacities, medium-sized improvements in PTSD symptoms, and small improvements in dissociation. Notably, however, patients with higher initial DES scores demonstrated the strongest and most consistent improvements. By Year 2, patients who entered the study with high dissociation demonstrated large improvements in emotion regulation, PTSD symptoms, dissociation, and patient-reported adaptive capacities. Patients with lower initial levels of dissociation also benefited at Year 2 relative to intake and demonstrated medium changes in emotion regulation and patient-reported adaptive capacities as well as small reductions in PTSD and dissociation symptoms. In addition, despite the chronicity and severity of NSSI in our sample, there were significant overall reductions in therapist-reported patient NSSI. Therapists' (PITQ-t) and patients' (PITQ-p) reports of improvements in adaptive capacities were directionally consistent, but differed in effect size. As is the case in therapeutic alliance (including among DD individuals; Cronin, Brand, & Mattanah, 2014), patients' reports of their adaptive capacities demonstrated stronger associations with other outcomes than did those of their therapists. Differences in reports of adaptive capacities may be because therapists' and patients' measures referred to different time frames (i.e., 6 months vs. 1 week) and/or patients' greater awareness of their daily experience and capacities. Therapists' ratings of their patients' adaptive capacities were found to covary with their assessment of patient's treatment stage, which suggests that higher PITQ-t scores are associated with later stages of treatment. Female patients demonstrated higher levels of emotional dysregulation and lower adaptive capacities at baseline. Results did not covary with age or native language of the participant's country, which suggests that the psychoeducation program had a similar impact regardless of age or native language.

This program was designed to facilitate symptom management and patient stabilization, targeting unsafe behaviors as well as the symptoms and emotions that contribute to them. We were generally successful in recruiting patients who were in the early stabilization stages of treatment; 85% of the partici-

pants were judged by their therapists to be working on symptom management and stabilization at intake. We received feedback from patients and therapists that the educational materials were relevant, clear, and useful for patients struggling with safety and symptom stabilization (see the Supplementary Materials for examples of specific feedback; analysis of qualitative and quantitative patient feedback is forthcoming).

Improving DD patients' capacity for emotion regulation is foundational for their recovery (Brand et al., 2012; ISSTD et al., 2011), as increased capacity for emotion regulation enables DD patients to tolerate painful emotions, thereby reducing their reliance on NSSI, other unsafe behaviors, and dissociation to manage overwhelming emotions related to traumatic intrusions and compartmentalized self-states. Consistent with this view, we found that significant improvements in emotion regulation were accompanied by improvements in PTSD symptoms, dissociation, and NSSI.

As expected for DD patients in early treatment, our sample had high levels of NSSI that would have resulted in most of these patients being excluded from typical treatment studies. Even the most chronically self-injuring patients appeared to benefit. For example, the therapists of the three patients who had the highest reported NSSI at intake (self-injuring approximately 100, 125, and 150 times in the last 6 months) reported their patients' NSSI had decreased considerably by the end of the program (self-injuring 0, 10, and 10 times, respectively, in the last 6 months). This is a crucial finding, as highly self-injurious patients are largely excluded from treatment studies yet are often the most challenging to treat (Brand, 2001).

At the beginning of the study, therapists reported that their patients averaged .39 suicide attempts in the prior 6 months ( $SD = 1.54$ ) and required an average of 22.27 days of hospitalization compared to a mean of 0.17 attempts and 11.50 days of hospitalization 2 years later. The reduction in suicide attempts is important given the high suicidality among DD patients, which often necessitates intensive intervention and is likely associated with impairment (Brand et al., 2013, Foote et al., 2008). It is possible that these changes in patients' safety may reflect underlying improvements in emotion regulation, which was a target of this program. These are promising findings for improved management of safety in this severely and chronically self-injuring group of patients.

Despite improvements, most patients continued to report levels of symptoms that implied need for further treatment. This is consistent with treatment outcome data for evidence-based PTSD treatments: A review of randomized controlled trials (RCTs) for military PTSD found that two-thirds of the patients who received treatment still met criteria for PTSD after treatment, despite those studies' exclusion of patients with the severe symptoms and comorbidities common in the current sample (Steenkamp, Litz, Hoge, & Marmar, 2015). This highlights the significance of the current study's findings: Participation in the TOP DD Network program was associated with significant benefits among highly self-injuring,



chronically ill, severely symptomatic DD patients, a population rarely targeted or included in treatment studies.

Compared to participants with lower levels of dissociation, the most highly dissociative among our DD patients demonstrated the greatest improvements. The high dissociation group began with higher levels of symptoms, more difficulties with emotion regulation, and lower levels of adaptive capacities, yet they demonstrated faster and greater improvement than the low dissociation group. These data show that treatment that includes emphasis on providing psychoeducation and stabilization-focused adaptive self-regulation skills can result in meaningful improvements in quality of life for even the most symptomatic and self-injurious DD patients. Although it is possible that regression to the mean contributed to these changes, these data also suggest that, although the program was associated with benefits for all DD patients, it may be especially beneficial to those with high levels of dissociation.

The strengths of the study included a large international sample, inclusion of all DD patients regardless of symptom severity, use of therapist and patient reports, and a standardized intervention using a prospective, longitudinal design. The TOP DD Network program was developed with input and feedback from DD patients and expert DD clinicians in collaboration with researchers (see the Supplementary Materials for additional information about the program's content).

Several design issues constrain our interpretations. Therapists may have shown a selection bias and invited patients who were especially motivated for treatment, and the sample population consisted predominantly of female Caucasian patients. Thus, these results may not generalize to all outpatients with complex DDs. The patients received clinical diagnoses of DD by their therapists rather than by using validated diagnostic instruments such as the Structured Clinical Interview for Dissociative Disorders–Revised (Steinberg, 1994). It is possible that use of these measures would have led us to exclude some participants. For example, given the relatively low DES scores in the low DES group, some of these individuals may have other disorders, such as the dissociative subtype of PTSD or borderline personality disorder with relatively high levels of dissociation, rather than a DD. Our study design did not permit assessment of regression to the mean, expectancy bias, changes due to individual therapy or medications, or other possible causes for observed changes. We cannot definitively make causal inferences without a comparison group. However, the strength and breadth of the outcome data are consistent with benefit of the program itself, particularly for commonly refractory symptoms such as NSSI. Finally, other than what the program itself provided, we did not control for therapists' training. Despite the likely heterogeneity of therapists' training, we found a wide range of improvements, suggesting that the program may be beneficial to DD patients regardless of their therapists' training.

Future work should examine whether there are symptom reductions and/or cost savings for patients who participate in this program beyond those that have been found for individual DD

therapy alone. Future work could also investigate whether patients' and therapists' knowledge about managing safety and symptoms increased over time, whether patients' use of symptom management skills increased over time, whether there is a dose-effect relationship between patients' involvement with program materials and outcomes, and whether or how preintervention therapist training contributes to patient participants' progress. Patient and therapist feedback is informing the next iteration of the TOP DD Network program, which will be studied as part of a randomized controlled trial.

Future studies should strive to increase representation of groups underrepresented in the current study. In addition, some study participants indicated they had already stabilized safety and thus found the focus on safety unhelpful and dropped out of the study. Future stabilization programs should screen for early stage patients.

In view of the high costs associated with DD treatment, both in terms of burden of disease and costs to the healthcare system, it is exciting that this relatively inexpensive online program was shown to be associated with significant improvements for the most symptomatic DD patients. It is particularly encouraging that these improvements were found in a sample that included patients irrespective of safety issues, comorbid conditions, and symptom severity, suggesting a broad applicability of this intervention. Finally, the prospective, longitudinal data presented here further underscore that DD patients can be meaningfully helped when treated with the phasic trauma treatment model exemplified by the ISSTD Treatment Guidelines and expert consensus.

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