TREATMENT ENGAGEMENT AND RETENTION IN PATIENTS WITH PTSD

Shannon Kehle-Forbes, PhD

March 20, 2019

PTSD Consultation Program Lecture Series

AGENDA

1. Brief review of PTSD psychotherapy dropout literature

2. Introduction to DECIDE study and methods

3. DECIDE findings
   1. The many similarities
   2. Therapeutic alliance
   3. Symptoms
   4. Life outside therapy
   5. Experience with treatment components

4. Implications

5. Questions

ACKNOWLEDGMENTS

Collaborators

- Princess Ackland
- Kate Chard
- Edna Foa
- Heather Gerould
- Alexandra Lyon
- Laura Meis
- Robert Orazem
- Melissa Polusny
- Paula Schnurr
- Michele Spoont
- Helen Valenstein-Mah
- Susan Zickmund

THE PROBLEM OF DROPOUT

About 1/3 of Veteran who initiate don't complete PE and CPT

- Not unique to PE/CPT – trauma-focus of treatment not related to dropout
- Some evidence that Present Centered Therapy (PCT) has lower dropout rates

Majority of Veterans who drop out don't improve

- Dropout typically occurs prior to symptom change; those who drop out experience smaller symptom reductions
- There is evidence that a subset (about one-third) of non-completers may experience meaningful symptom improvement

Other negative impacts of dropout

- Negatively impacts provider morale
- Expensive & limits access to treatment
- May increase stigma; decrease likelihood of future treatment seeking

SZAFRANSKI ET AL, 2017; GOETTER ET AL,, 2015; KEHLE-FORBES ET AL, 2016; BERKE ET AL., 2019

THE PROBLEM OF DROPOUT

Lots of study, but few consistent predictors of PE/CPT dropout

- Younger age repeatedly found to be associated with fewer session
- Accumulating evidence that group treatment associated with fewer sessions than individual
- Greater severity of symptoms at baseline may be associated with dropout

Potentially modifiable factors have been harder to consistently identify

- Many "one-off" findings of predictors (treatment credibility, readiness to change, etc.)

Recent qualitative work has helped to elucidate the issue

- Interviews with 27 non-completers found therapy-related barriers (lack of buy-in to rationale / specific tasks, belief that the treatment wasn't working, alliance problems, switching to other treatments) most commonly reported
- No comparison to completers – unclear which of these are uniquely related to treatment completion

HUNDT ET AL, 2016; SZAFRANSKI ET AL, 2017; GOETTER ET AL, 2015; KEHLE-FORBES ET AL, 2016; BERKE ET AL. 2019; MEIS ET AL, 2019;

THE DECIDE STUDY

Qualitative study with these specific aims:

- Understand reasons for premature dropout from PE and CPT from both the patient and the provider perspective

- Identify factors that actively facilitate PE and CPT completion

- Develop an intervention framework that can be used to improve retention in PE and CPT

DECIDE METHOD

Conducted semi-structured interviews with national sample:
- 68 PE and CPT dropouts
- 60 PE and CPT completers
- (33 providers of PE and CPT dropouts)

Purposively sampled for:
- Time of dropout (sessions 1-2 versus sessions 3-6)
- Group vs. individual CPT
- Race / ethnicity
- Posttreatment PCL (for completers)

Veteran Demographics:
- 34% women
- 25% African American; 14.1% Hispanic
- 33% Vietnam era
- 60 PE interviews; 39 individual CPT interviews; 29 group CPT interviews

METHOD

Interviews within three months of dropout, focused on:

- Veterans' perception of treatment experience
- Early treatment (knowledge, expectations, and hesitations)
- Process of dropout (ebb and flow of dropout thoughts and behaviors)
- Treatment experience (reaction to components, therapeutic alliance, response)
- Social influences and logistical barriers

Mixed inductive & deductive coding approach

- Top level codes derived from conceptual model
- 2nd & 3rd level codes derived from text

Constant comparative method used to compare differences between completers & dropouts

DECIDE RESULTS

Top Level Codes:
1. Reactions to Treatment
2. Therapeutic Skill & Alliance
3. Symptoms
4. Life Outside of PE/CPT
5. Beliefs
6. Interventions

DECIDE RESULTS

COMMONALITIES ACROSS DROPOUTS AND COMPLETERS

Thought therapist was skilled

Liked therapist, caring, genuine

Major & minor life stressors present

Perceived worsening

Experience of approaching trauma content

Ambivalence & efforts to combat ambivalence

Expectation of effectiveness / helpfulness

Good information exchange / liked being "upfront"

Perceived good support from others

Reaction to first session

What it was like to do the treatment component

Apprehension about treatment / worries

Good non-specific rapport

Logistical barriers (travel, appt times)

Anticipatory anxiety

Understanding of rationale

Expectation of what it is going to be like

DECIDE RESULTS – THERAPEUTIC ALLIANCE

❖Completers' therapists provided <u>treatment-specific support</u>; built alliance in context of treatment

- Responsive to needs
- Flexible in treatment delivery
- Encouraged patient autonomy and control
- Repeatedly encouraged staying in treatment
- Provided "cheerleading" – pointed out progress to patient

❖Delivery was <u>patient – not protocol – centered</u>. Made patients feel heard, in control, and bonded to therapist

DECIDE RESULTS – THERAPEUTIC ALLIANCE

❖ Specific strategies used to build rapport:

- Flexible in talking when they would talk about things, could talk about them later
- Emphasized autonomy: not going to make you do anything you don't want to do, give breaks, encourage to take your time,
- Reminding vet of reasons started treatment (e.g., family),
- Analyzed/problem-solved "*why don't you think you could do this? How can we get this done?*"
- Didn't engage in negative behaviors: didn't get angry with patient, didn't badger
- Expressed faith in patient to complete, non-judgmental, humor, modeling (imperfect, therapist's fears)
- Checking in "*are you okay with this*"

DECIDE RESULTS – THERAPEUTIC ALLIANCE

"[He] left a lot of decisions up to me. I felt like he was taking my experience into consideration and not just his diagnosis... I felt like he allowed me to take part in what I felt was going to work for me."

-Completer

DECIDE RESULTS – THERAPEUTIC ALLIANCE

❖Completers & therapists were "*in the trenches*" together. Completers often referred to their relationship with their therapist as helping them push through tough times and complete therapy:

- Mutual commitment
- Not wanting to disappoint therapist
- Wanted therapist to like him/her
- Therapist invested in veteran so had to reciprocate
- Easy to talk to, so helped veteran talk
- Feeling that provider cared made veteran feel able to open up
- Provider investment in the relationship; therapist cared

❖Came from rapport-building in context of treatment

DECIDE RESULTS – THERAPEUTIC ALLIANCE

"I just didn't want to disappoint him, that we were going through the treatment. I didn't do the homework one time because it was so rough, it was so difficult. And I apologized to him. And I told him that I was anxious about going that day… But he, again, made me feel comfortable and he said I don't want you to ever be anxious about coming here. We're doing this for you."

- Completer

DECIDE RESULTS – THERAPEUTIC ALLIANCE

❖Non-completers' therapists were more rigid in their delivery, more strictly adherent to protocol

- Veterans felt as though their therapists didn't know or understand them
- Cause them to question providers' expertise
- Treatment seemed impersonal
- Lack of connection result of overly strict adherence

DECIDE RESULTS – THERAPEUTIC ALLIANCE

"Like I said, there was no personal questions about my symptoms and how I live. She actually still doesn't know me."

-Non-Completer

DECIDE RESULTS - SYMPTOMS

❖ Almost all participants perceived that they were getting worse during PE/CPT – <u>meaning</u> of worsening differed

- Non-completers feared impact on functioning & safety
- Preferred pretreatment level of functioning to risk of worsening, "*barely making it*"

"I don't know if there's a way to get a person mentally back from all of that reliving. I couldn't—I knew I wasn't what I wanted to be as far as school and in my family life after the sessions. It left me out there and I didn't know how to come back."

-Dropout

DECIDE RESULTS - SYMPTOMS

❖Non-completers perceived worsening to indicate that the treatment wasn't going to work, while completers viewed it as part of the process

"Once I started repeating them constantly I would wake up two, three, sometimes four times a week with nightmares… I assume that was supposed to happen."

-Completer

❖Few non-completers reported symptom improvement
- Increased insight / understanding mentioned for those that reported benefits
- Non-completers expected early symptom improvement & to feel better after session; lack taken as proof that treatment wasn't working

DECIDE RESULTS – LIFE OUTSIDE PE/CPT

❖Non-completers feared the impact of participation on functioning, particularly relationships
- No noticeable difference in actual impact on relationships
- Non-completers' support more likely to bring up negative changes seen in Veteran, completers' support more likely to mention positive change

❖Non-completers more likely to let life stressors (major & minor) and day-to-day responsibilities interfere with treatment
- Become overwhelmed / unable to cope with competing demands
- Prioritize other responsibilities
- Sometimes used as an excuse or justification

DECIDE RESULTS – LIFE OUTSIDE PE/CPT

"I had surgery and it was just convenient not to go. It was like okay, well, I'll just use that as my excuse."

- Non-completer

DECIDE RESULTS – LIFE OUTSIDE PE/CPT

❖Type of social support differed between completers and non-completers

- Mirrored findings from therapists; support from completers was more directive, specific to PE/CPT
- Non-completer support was general emotional support

"Everyone just wants the best for me, and so whatever decision I made they back me up on it. Everyone told me, "It's your decision. We'll support you.""

-Non-completer

DECIDE RESULTS – LIFE OUTSIDE PE/CPT

❖Completers used concurrent treatment to stay in PE/CPT

- Entire care team aligned around completion

- Meds strategically used to manage symptom increases (especially sleep)

- Non-EBP therapist used to help manage competing stressors, manage symptoms, and provide support

"She would still make sure that I was in therapy doing the Prolonged Exposure… She was always making sure that it was going okay and that, you know, if I needed anything that she'd be there."

-Completer

DECIDE RESULTS – REACTION TO TREATMENT

❖ Treatment participation was difficult for vast majority: *"crying", "brought up a lot of emotions", "sickening", "felt weak", "felt embarrassed"*

❖ Completers better able to keep longer-term benefit in mind when approaching trauma content. Had *"the better time"* in mind
- Kept going long enough to see improvement, which strengthened resolve.

❖ Non-completers wanted to stop at beginning stages of approaching trauma content; *"Uncomfortable so I stopped."*
- Increased distress evidence that treatment was not working / rationale was incorrect
- Expectation of early symptom improvement & leaving session feeling better

❖ Difference could be in understanding, support, higher tolerance for distress, and/or interpretation of consequences.

DECIDE RESULTS – REACTIONS TO TREATMENT

"By the third session I just kind of figured I'm not changed a lot and I don't want the paperwork so I'm just not going to go."

-Non-completer

DECIDE RESULTS – REACTION TO TREATMENT

❖Differences in reactions to structure
- Non-completers felt too fast-pasted, too soon to talk about the trauma.
- Didn't think it was long enough to address problems
- Used it to discredit treatment; provider must not know what they are talking about

❖Dropouts talked more about structure of treatment: "*too focused on trauma*", "*not personalized*", "*repetitive and rigid*", *felt like* "*class*", "*scripted*"

❖Nearly all completers liked their groups; non-completers were mixed
- Completers felt they were helping others, were challenged, liked the support
- Non-completers varied: helpful and provided support, didn't fit in, group members were annoying, or they preferred one-on-one

DECIDE RESULTS – BELIEFS

❖No clear difference in understanding and buy-in of rationale

❖Non-completers who didn't believe had specific reasons why not, why completers were more broadly skeptical
- Doesn't fit with past experience; can't differentiate from past treatment experiences
- Use early treatment experience to discredit rationale
- Timeline seemed unrealistic

❖Non-completers skeptical or promised level of improvement, especially in timeline

"It didn't seem realistic. Ten sessions and I'll stop doing that."

- Non-completer

DECIDE RESULTS - BELIEFS

❖Non-completers' worries about treatment more severe

• Trouble functioning, deep depression, suicidality / hurting oneself, being unsafe / trauma reoccurring, hurting others, losing control, relapsing on alcohol or drugs.

• Completers had similar number of fears, but had less severe shorter lasting consequences.

"[I was worried it would] make a wreck of me; I was already depressed and really scared of myself. Scared of my own damn demons."

- Non-completer

DECIDE RESULTS - INTERVENTIONS

❖Non-completers <u>and</u> completers experienced ambivalence, symptom exacerbation, and other problems - but disclosure was selective

- Didn't disclose because didn't want to make therapist feel bad or be judged
- Non-completers did not disclose until decision was made – informing of choice; didn't want to have their minds changed.
- Non-completers often were not up front about real reason for discontinuation

"Actually, I told her that family members have surprised me from Puerto Rico and they're here, and that was a lie. Nobody was here. I just couldn't go back."

– Non-completer

DECIDE RESULTS – A SURPRISE

❖Sizable minority (10-15%) of Veterans who don't think / don't realize they have discontinued

❖Prototypical "confused" dropout:

▪ Long treatment history; very compliant in attending sessions and readily follow therapists' treatment recommendations

▪ Didn't understand that PE / CPT is different than what they have been doing; often continuation with same therapist

▪ Behaved the same in PE / CPT as they have in other treatments (e.g., no homework; focus on present concerns); didn't understand expectations

▪ Provider views avoidance and recommends terminating – Veteran either goes along with provider recommendation or doesn't realize change in treatment approach

▪ Many continue in another type of therapy with same provider

▪ Did not have thoughts of dropping out prior to discontinuation

DECIDE - LIMITATIONS

❖Retrospective design

❖Not all completers improved – will need to examine outcomes in intervention study

❖Group experience differs from individual

❖Patient perspective only in this analysis

DECIDE - IMPLICATIONS

❖Developing rapport in context of therapy essential
- Patient-centered approach, make it work for specific patient
- Flexibility
- Patient control & autonomy
- Both parties share responsibility for successful completion

❖Eliciting expectations and perceived consequences of symptom change (worsening & lack of improvement)
- Challenge beliefs
- Develop plan for managing thoughts as they arrive and/or staving off perceived consequences throughout treatment

❖Build PE/CPT specific support (engage full care team / existing support system)
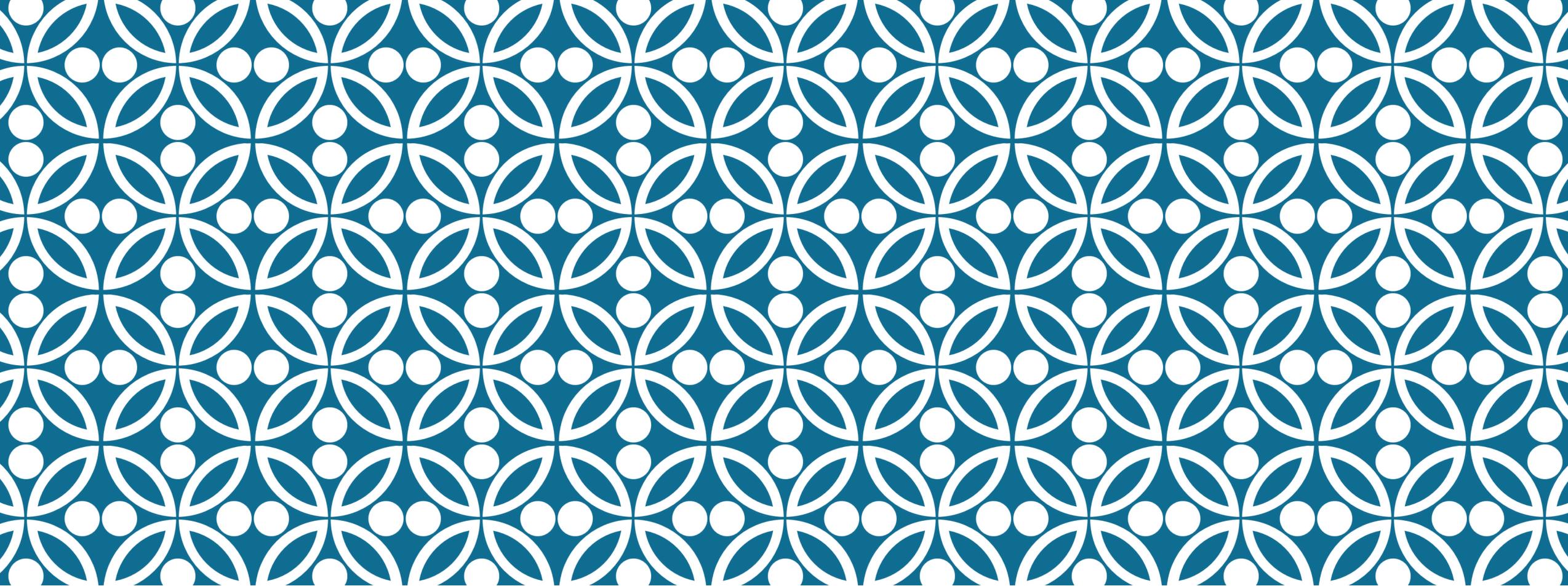
QUESTIONS & COMMENTS

Shannon.Kehle-Forbes@va.gov

PTSD PTSD Consultation Program
FOR PROVIDERS WHO TREAT VETERANS

(866) 948-7880 or PTSDconsult@va.gov

Please enter your questions in the Q&A box and be sure to include your email address.

The lines are muted to avoid background noise.

PTSD Consultation Program

FOR PROVIDERS WHO TREAT VETERANS

(866) 948-7880 or PTSDconsult@va.gov

Employee Education System

VHA TRAIN

Welcome users of VHA TRAIN!

To obtain continuing education credit please return to www.vha.train.org after the lecture.

TRAIN help desk: VHATRAIN@va.gov

PTSD PTSD Consultation Program
FOR PROVIDERS WHO TREAT VETERANS

(866) 948-7880 or PTSDconsult@va.gov

CEU Process for users of VHA TRAIN (non-VA)

Registration—> Attendance —> Evaluation —> Certificate

Register in TRAIN.

Listen to the lecture.

Return to TRAIN for evaluation.
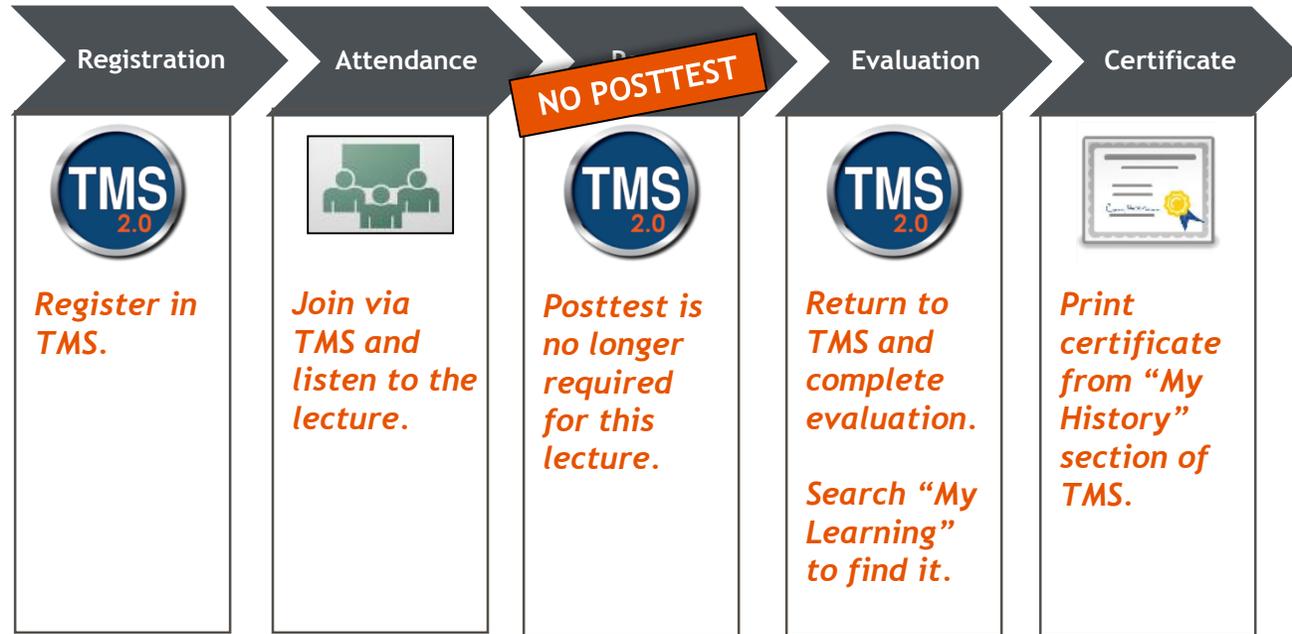
Follow the directions to print certificate.

TRAIN help desk: VHATRAIN@va.gov

PTSD PTSD Consultation Program
FOR PROVIDERS WHO TREAT VETERANS

(866) 948-7880 or PTSDconsult@va.gov

CEU Process (for VA employees)

Registration	Attendance	NO POSTTEST	Evaluation	Certificate
Register in TMS.	Join via TMS and listen to the lecture.	Posttest is no longer required for this lecture.	Return to TMS and complete evaluation. Search "My Learning" to find it.	Print certificate from "My History" section of TMS.

PTSD Consultation Program
FOR PROVIDERS WHO TREAT VETERANS

✉ PTSDconsult@va.gov

📞 (866) 948-7880

🌐 www.ptsd.va.gov/consult

PTSD Consultation Program
FOR PROVIDERS WHO TREAT VETERANS

(866) 948-7880 or PTSDconsult@va.gov

FREE TRAINING IN
PROLONGED EXPOSURE THERAPY
FOR COMMUNITY PROVIDERS WHO TREAT VETERANS WITH PTSD

Non-VA Providers:

Download a flyer from the Files pod for more information.

PTSD **PTSD Consultation Program**
FOR PROVIDERS WHO TREAT VETERANS

(866) 948-7880 or PTSDconsult@va.gov

UPCOMING TOPICS

SAVE THE DATE: Third Wednesday of the Month from 2-3PM (ET)

April 17	*PTSD Diagnostic Challenges*	Matthew Friedman, MD, PhD
May 15	*Moral Injury*	Sonya Norman, PhD

Lectures for June through December will be announced soon.

For more information and to subscribe to announcements and reminders go to
www.ptsd.va.gov/consult