Trauma-Informed Care for People Living with Dementia

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NADRC
National Alzheimer’s and Dementia Resource Center

ACL
Administration for Community Living

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Post-Traumatic Stress Disorder (PTSD) & Dementia: A Trauma-Informed Care Approach

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What is Trauma-Informed Care

“Trauma-informed care (TIC) is a perspective that acknowledges the pervasive influence and impact of trauma on an individual, their provider, and the organization delivering case management and other supportive services.” Dinnen, Kane & Cook, 2014
What is Trauma?

DSM – 5 Criterion A: Exposure to actual or threatened death, serious injury, or sexual violence by:

1. Direct exposure
2. Witnessing, in person
3. Learning about it happening to a close family member or friend
4. Experiencing repeated or extreme aversive details of trauma (often work-related)
Trauma, PTSD, Resilience

• Not all trauma survivors develop PTSD
  – PTSD, Major Depressive Disorder (MDD), Substance Use Disorders (SUD)
  – Sub-threshold PTSD

• Other outcomes that may be seen in trauma survivors
  – Limited trust impacting family relationships and other attachments
  – Personality traits built on survival

• Resilience and trauma survivors
Diagnosing PTSD
DSM-5: PTSD Criteria

A. Big-T Trauma
B. Intrusive symptoms associated with Traumatic event
C. Avoidance of stimuli associated with Trauma
D. Negative changes in Cognitions and Mood
E. Changes in Arousal and Reactivity
F. Duration of >1 month
G. Significant Impairment
H. Not due to another medical condition
Common Posttraumatic Reactions

Feelings of guilt and shame

Aggressive behavior

Suicidal thoughts
Dementia

PTSD

Neurocognitive Disorder (NCD)

1.77 – 2.31x more likely

Worse symptoms

1 – Yaffe et al., 2010
2 – Hamilton & Workman, 1998
3 – Mittal et al., 2001
mTBI₁
Mild Traumatic Brain Injury

PTSD

1.77 – 2.31x more likely

Worse symptoms

NCD

SUD₂

Dementia

1 – Bryant et al, 2010
2 – Lemke & Schaefer, 2010
Back to Trauma-Informed Care.....
Who is Trauma-Informed Care for?

- Clients with PTSD and without a diagnosis of PTSD
- Veterans who have reported trauma histories and those with UN-reported trauma histories
- All staff and leadership at every level of the provider organization
How can Trauma-Informed Care lead Veterans toward recovery?
Key Steps

“Meeting clients’ (Veterans or not) needs in a safe, collaborative, and compassionate manner; preventing treatment practices that retraumatize people with histories of trauma who are seeking help or receiving services; building on the strength and resilience of the client in the context of their environments and communities; and endorsing trauma-informed principles in agencies through support, consultation, and supervision of staff.”

Realizing, Recognizing, and Responding

Realizing the prevalence of trauma

Recognizing how trauma affects all individuals involved with the program, organization, or system, including its own workforce

Responding by putting this knowledge into practice.
Basic Understanding of Trauma

• Ask for help if you need it!

• PTSD Consultation Program:
  – PTSDConsult@va.gov
  – 866-948-7880
Removing Barriers to TIC by Screening for Trauma
Fears related to Screening and Assessing for Trauma

- Lack of training
- Does not know how to respond therapeutically
- Does not know how to provide trauma treatments
- Focus is not on PTSD
Screen for Trauma and Symptoms of Trauma

• Before screening, work with your organization to ensure processes are in place for responding to the results of screeners

• Basic screening instruments:
  – Life Events Checklist (LEC-5):
  – PC-PTSD (5 item PTSD screen)
    • [https://www.ptsd.va.gov/professional/assessment/screens/pc-ptsd.asp](https://www.ptsd.va.gov/professional/assessment/screens/pc-ptsd.asp)
  – PHQ-9
Using TIC to inform Dementia Care

Dementia vs. PTSD

Behavioral Excess: Agitation, Aggression, Vocalizations, Delusions/Hallucinations

Behavioral Deficits: Apathy, Depression
Who and how can we obtain support in this process?
National Center for PTSD Resources

• Trauma-Informed Care fact sheet
  – https://www ptsd va gov/professional/continuing ed/dementia ptsd asp
More Information:
National Center for PTSD Website

www.ptsd.va.gov
PTSD Consultation Program
FOR PROVIDERS WHO TREAT VETERANS

Who can contact us?
Any provider treating Veterans with PTSD.

Who are the consultants?
Experts at the National Center for PTSD including psychologists, social workers, physicians, and pharmacists.

Ask us about
- Evidence-Based Treatment
- Medications
- Clinical Management
- Resources
- Assessment
- Referrals
- Educational Opportunities
- Improving Care
- Transitioning Veterans to VA Care

What can you expect?
- It's easy to make a request
- Responses are quick
- Questions are answered by email or phone
- Calls are scheduled at your convenience

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

There is no charge for these services.

WWW.PTSD.VA.GOV

National Center for PTSD
POSTTRAMATIC STRESS DISORDER
Trauma-Informed Care
for People Living with Dementia

A PRESENTATION BY:
Andrea Korsunsky
Director, Center for Dementia Care
Jewish Family and Children’s Services strengthens individuals, families, and community across the Bay Area and is a lifeline for people facing personal crises or challenges.

1,000
Holocaust survivors served annually throughout the Bay Area

2,800
Hours of care management, counseling, and consultation provided annually
Why It’s Different: Trauma + Dementia

Dementia
Abilities affected by dementia:
• Judgment/reasoning
• Communication
• Orientation- unable to reference recent events to calm self
• Insight into current circumstances, limitations, and quality of life issues

Trauma
Abilities needed to cope with a trauma:
• Judgment/reasoning- to navigate getting help
• Communication- to process emotions
• Orientation/ability to reassure self in the moment
• Determination/survivor mentality
Other Challenges

• Adult children are protective of their parent due to trauma experienced in the Holocaust
• Low confidence in “systems”- difficulty with trust
• Advanced age – complex medical conditions
• Difficulty differentiating behaviors associated with trauma and dementia
Common Practices to Avoid

• Limit-setting
• “Doctor’s orders”
• Strict boundaries related to time
Family Perspective

• Dementia affects the whole family for a prolonged period of time
• Stigma
• Dementia affects all aspects of a person’s care needs—emotional, physical, financial
• Family dynamics/complicated relationships related to the parent experiencing trauma from the holocaust
Strategies

• Ask the family their perspective and build your care plan based on this initial conversation - flexibility is critical

• Compartmentalize - step by step process

• Regular communication and meetings
  – Typically, we are taught that one family member must be the spokesperson - that may not work in this case.
Practical Approaches

- Apply Best Practices: Person-Centered Approach
- Avoid Known Triggers
- Understand Therapeutic Lying
- Adapt Trauma-Informed Care
Apply Best Practices

• Person-Centered Care
  – Understanding that all experiences from the Holocaust are individual
  – Ask questions about things you are unclear about, do the research

• Behavior is Communication
  – Responding to the emotion behind what is being said
  – Even more important for people who have survived the Holocaust
  – Anticipate needs
Avoid Known Triggers

- Doctors/lab coats
- Authoritative approach
- Dogs
- Showers
- Strong odors/chemicals/bleach
- Sirens/loud noises
What about the triggers which cannot be avoided?

• Needles
  – DON’T rush through with physical restraint
  – DON’T try to convince them why it is necessary
  – DO engage in friendly conversation throughout – talk about points of interest
  – DO distract by offering a headset with classical music
  – DO engage other senses: aromatherapy, other forms of touch to distract, taste- provide a favorite snack

• Medical transportation
  – Find ways to avoid medical transportation if at all possible i.e. non-emergency transportation
  – Avoid use of the word “Transport”-- Instead describe the outcome: “we are going to get help” “you’re invited to see your care team” “we will go together”
  – Accompany the person in the ambulance and explain the situation to medics

• Sterile-looking environments
  – Soften the appearance, integrate bright colors, flowers, art.
  – Suggest to families that they bring a small photo album or distract by offering a favorite magazine, headset with music
  – Give them something to hold- which symbolizes security, weighted blankets are helpful for people with dementia
  – Focus on body language
Re-traumatization

• You must understand a patient’s personal experience
Therapeutic Lying

• What does it mean to have dementia?
  – “A shift in the way a person experiences the world around them” - Dr. G Allen Power
    • We must adapt, we cannot expect the person with dementia to adapt
  – Explain to families that their loved one relies on them to feel safe, supported and validated.
    • To illustrate the importance of not sharing the full truth/situation, explore the family member’s experience with failed attempts at explaining situations/reasoning/judgment
Apply 6 key principals of Trauma Informed Care to Holocaust Survivors with Dementia

1. Safety
2. Trustworthiness and transparency
3. Peer support
4. Collaboration and mutuality
5. Empowerment, voice and choice
6. Cultural, historic, and gender issues
1. Safety

- Be mindful of known triggers based on past experiences
- Be flexible and accommodate those needs from the beginning
- Show safety and support through body language
- Ask what safety means to the individual
- View trauma related symptoms/behaviors as attempts to cope
- Environment- consider the where and when interview/service is occurring
- Having awareness of an individual’s discomfort or unease
2. Trustworthiness and Transparency

• Be descriptive in outlining your goals from the beginning- meet with family separately and discuss the reality of what support they can offer

• Ask questions
  – Ask the person with dementia what they feel is the best part of their day and integrate into the plan of care

• Listen and echo what you hear
3. Peer Support

- Normalize the situation
- Integrate follow-up support into your care plan/discharge plan
  - Jewish Family Services
  - Synagogue
  - Restitution/ home care services
4. Collaboration and Mutuality

• All family members on board

• Strengthen existing support systems by facilitating communication and developing a plan
  – Educate that the behaviors are not intentional
  – Help the family differentiate long time personality patterns related to surviving the holocaust and behaviors associated with dementia
5. Empowerment, Voice and Choice

- Support autonomy - this is especially difficult once a person has dementia
- Ask questions
- Listen
6. Cultural, Historic, and Gender Issues

• Understand the background

• Avoid known triggers based on the person’s own experiences

• Don’t rely on the patient’s ability to express
Review Key Concepts
Sources

• Dementia Beyond Disease: Enhancing Well-being. G. Allen Power, 2014

• Substance Abuse and Mental Health Services Administration,
  – https://www.samhsa.gov/nctic/trauma-interventions

• Administration for Community Living (ACL) Guidance to the Aging Services Network: ACL Guidance for Outreach and Providing Services for Holocaust Survivors
For questions, contact:

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