

Person-Centered, Trauma-Informed Care for Family Caregivers of Older Adults with a History of Trauma: Needs, Challenges, and Emerging Approaches

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Definition of Person-Centered, Trauma-Informed (PCTI)



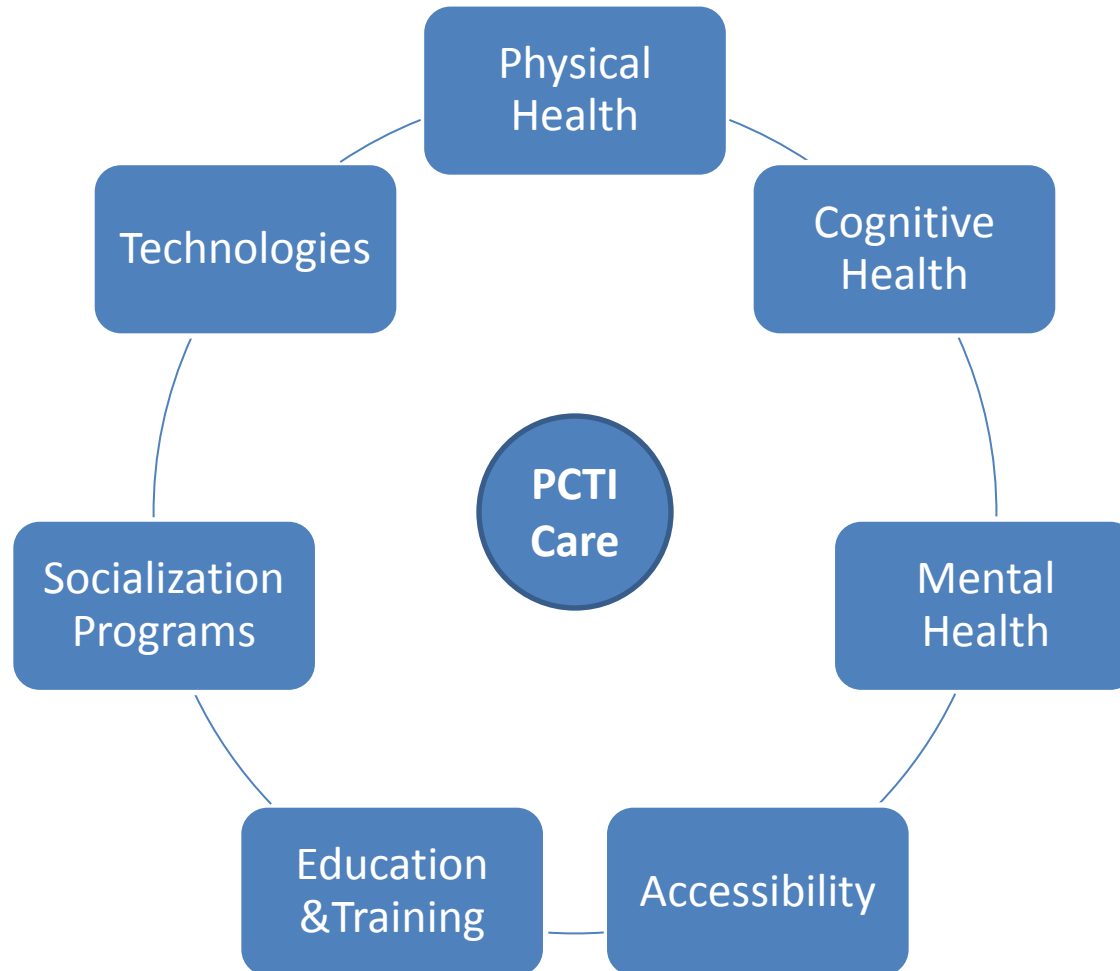
A holistic approach to service provision that promotes the dignity, strength, and empowerment of trauma victims by incorporating knowledge about the role of trauma in victims' lives into agency programs, policies, and procedures.

The JFNA Center for Advancing Holocaust Survivor Care's Goals

- Promote PCTI innovations for Holocaust survivors.
- Build national capacity to provide PCTI-based services to Holocaust survivors.
- Advance PCTI care in the broader Aging Services Network to serve older adults.



Innovative Programs



Examples of Older Adults Victims of Trauma

- Veterans
- Refugees
- Survivors of Domestic Violence
- Survivors of Sexual Abuse
- Survivors Elder Abuse
- Survivors of Child Abuse
- Survivors of Human Trafficking





Government Support for Caregivers

Greg Link, Director
Office of Supportive & Caregiver Services
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There are only four kinds of people in the world:

Those who have been caregivers

Those who are currently caregivers

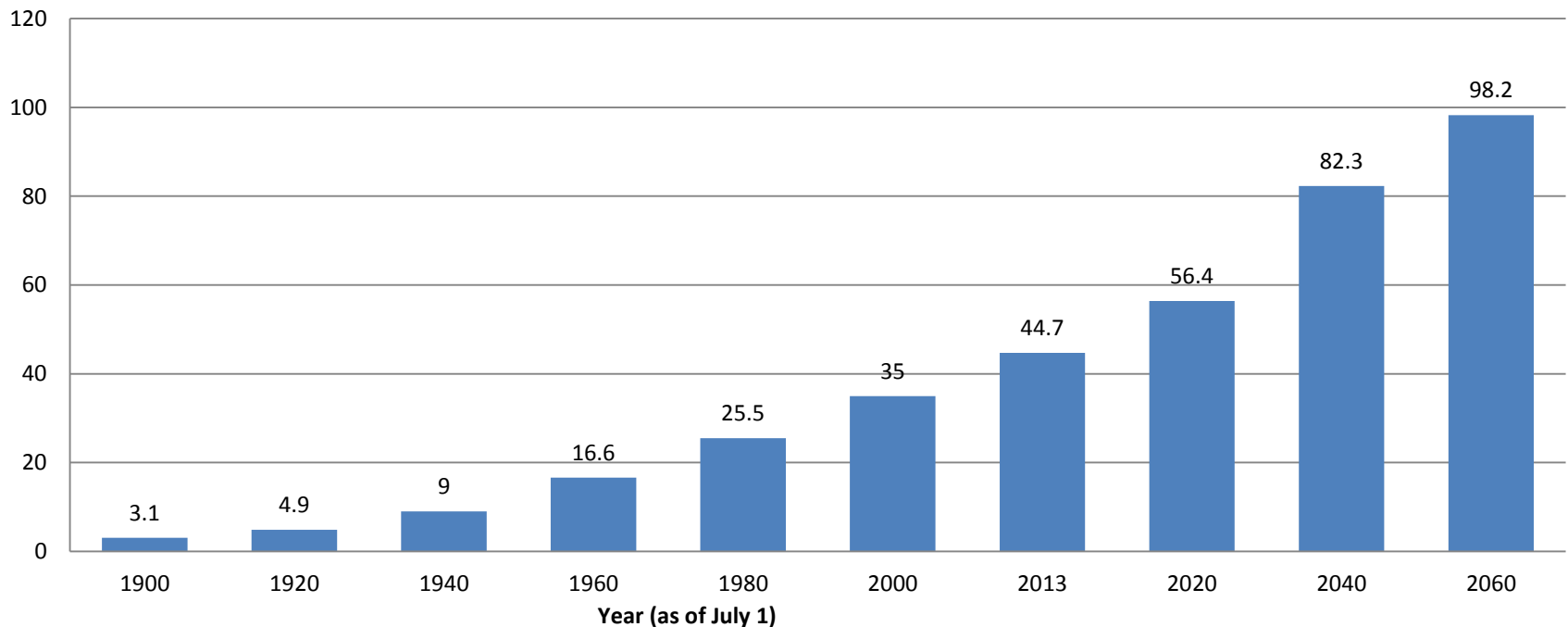
Those who will be caregivers, and

Those who will need caregivers

First Lady, Rosalynn Carter

Population Projection: Our Aging Population

Figure 1: Number of Persons 65+, 1900 to 2060 (numbers in millions)



Source: U.S. Census Bureau, Population Estimates and Projections

Family Caregiving: The Numbers

- 44 million adults (18.2%) in the U.S. provided care to an older adult or adult with disabilities in the prior year
 - Annual value of this care estimated \$470 B; double the combined cost of home and nursing home care in the US and equal to the total annual sales at Walmart
- 75% of all caregivers are female, and may spend as much as 50% more time providing care than males
- Nearly 1 in 10 caregivers is 75 years of age or older
 - 24% provide care for 5 years or more
- 82% of caregivers care for one other adult, while 15% care for 2 adults, and 3% for 3 or more adults

A Profile of the “Typical Caregiver”

- **Who they are**
 - 49 year old female
 - Caring for 69 year-old female relative
 - Needs help with a long-term physical condition
- **What they do**
 - Providing care for 4 years
 - 24.4 hours per week
 - Helps with 2 ADLs/4 IADLS
 - Do medical/nursing tasks
 - Has no assistance
- **Work and Career**
 - Is a H.S. grad/some college
 - Employed and working full time
 - Average household income: \$54,700
- **Care Receivers**
 - Live with the caregiver or close by
 - Hospitalized once in the past year

Family Caregiving: A Complex Experience

Caregiving can....

- Cause **anxiety/fear**
- Result in **depression**
- Be **exhausting**
- Be a source of **burden**
- Make one **angry**
- Become **overwhelming**
- Be **isolating**

Caregiving can also be....

- An **empowering** experience
- Greatly **appreciated**
- **Satisfying**
- A reason to **hope**
- A chance to **bond**
- An opportunity for **growth**

Family Caregivers Need....

- **Information** – about their situation; available services; their loved one's condition
- **Assistance** – in accessing supports and information available to them
- **Education and/or Counseling** – to help them better understand or cope with their caregiving responsibilities
- **Respite** – to give them a break to relax and refresh
- **Other goods and services** – to help address the unique needs their situations present

When working with family caregivers, remember...

- They might not always self-identify
- There might be more than one and each may play a different role
- Their experience as a caregiver can be influenced by the past
- Each caregiver's "career" has its own trajectory
- Their needs can change in an instant
- "Person-Centered" = "Caregiver Centered"

Programs to Support Family Caregivers

- National Family Caregiver Support Program (NFCSP)
- Lifespan Respite Care Program
- Alzheimer's Disease Supportive Services Programs (ADSSP)
- Alzheimer's Disease Initiative/Specialized Supportive Services (ADI/SSS) Programs
- VA Caregiver Support Program
- State and local programs/services

www.acl.gov/programs/support-caregivers

Helping Caregivers Find Help

- Eldercare Locator (www.eldercare.gov)
- National Respite Locator (www.archrespite.org/respitelocator)
- Aging and Disability Resource Centers ([ADRC](#))
- www.Alzheimers.gov
- VA Caregiver Support Program (www.caregiver.va.gov)

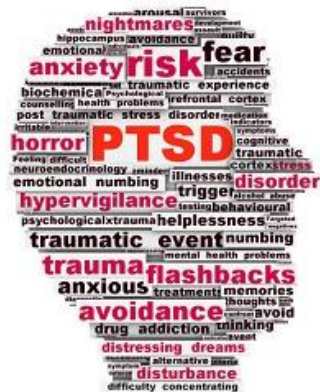
Supporting Caregivers of Veterans



Tara Giese, MSW, Sr. Program Manager
Lutheran Social Services of Minnesota
Caregiver Support and Respite Program

Definition of Trauma

Trauma results from exposure to an incident, or series of events, that is emotionally disturbing or life threatening.



Statistics

- 70% of adults in the United States have experienced a traumatic event at least once in their lives.
- 20% of these people go on to develop PTSD.
- Women are more likely to develop PTSD than Men.

PTSD and Older Adults

- Potential to deny mental or emotional issues
- Will often report physical symptoms and not disclose any other symptoms
- Will often deny or minimize reported trauma or symptoms



PTSD and Older Adults Cont.

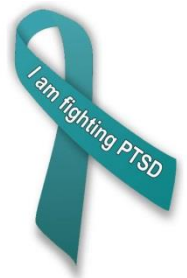
- Many older adults view having mental health issues as weakness.
- Many blame themselves for the trauma they experienced.
- Older adults may have more negative disclosure experiences earlier in life.

PTSD and Older Adults

- The normal aging process may reduce the experience of symptoms (ex. hearing loss may reduce startle responses).
- Retirement leaves more time to think and provides fewer distractions.
- Age-related medical problems can interact with PTSD symptoms.

PTSD and Older Adults

- Media coverage of war and tragedy can lead to flashbacks.
- Unhealthy methods of coping, such as drug and alcohol use, may catch up with older adults or be abandoned without being replaced by healthy coping methods.



Dementia and PTSD

- Because many people with dementia experience changes in personality, doctors don't always recognize PTSD symptoms and instead associate the unusual behavior with dementia; therefore PTSD often goes untreated.
- Memories of the traumatic experience may become stronger, or older adults may experience flashbacks.

PTSD and the Caregiver



Research shows that family caregivers can experience PTSD because of their caregiving experience.

Tips to Provide Family Caregivers

- PTSD Education
- Pace yourself
- Learn Positive Coping Skills
- Attend a Caregivers Support Group
- Respite care
- Take care of your Health
- Seek Professional help when needed both for yourself and your loved one
- Maintain social activities and important relationships
- Exercise
- Live one day at time
- Keep your sense of humor
- Self Care
- Maintain social activities and important relationships
- Exercise
- Live one day at time
- Keep your sense of humor
- Let others help



Person-Centered Care

- Develop individualized care plans.
- Involve the family, and the older adult if possible, in the care plan.
- Know the older adult's history.
- Flexibility is key. Have a plan B



Innovative Strategies

- Pet Therapy
- Art Therapy
- Physical Activity
- Field Trips
- Gardening
- Baking
- Volunteering
- Talking to other Veterans
- **JUST TALKING!**



Stanley



Paul



Jon



Paula





Supporting Caregivers of Holocaust Survivors

Debbie Rosenwein, MSW, LSW, Manager
Holocaust Services Department
Jewish Family Service Agency of Central
New Jersey

Overview of Presentation

- Unique needs of family caregivers
- Transmission of trauma – unique challenges of caregivers
- Impact of older adult's trauma experience on ability to receive care
- Providing PCTI care to family caregivers
- Sharing promising practices
 - Strategies, lessons learned, resources
 - Other applications

Emotions of Survivors after their Experience in Holocaust

- Death Imprint – Survivors witnessed brutality of death; images etched in mind
- Cognitive expectations – nightmares of persecution; Stress upon exposure to stimuli which symbolize Holocaust, i.e. stripes in clothes, wooden shoes
- Survivor's Guilt – Why am I still alive when my family has perished?
- Search for Meaning – Why atrocities happened; rationale
- Numbness – Inability to express emotions; defense mechanism used to avoid overwhelming/painful memories; creates withdrawal between victim and other human contact.
 - Number of survivors suffer from Post Traumatic Stress Disorder (PTSD) where they continue to be affected by experiences of persecution which can adversely affect their lives and can be passed to second generation, especially when living in same household.

New Ground

Uncharted territory – older adults did not survive Holocaust; no family; few, if any support networks existed



Immigrant Experience – culture and Language barrier



After the Holocaust, when survivors married and started families.....

Transmission of Trauma

...sometimes entered into loveless marriages with desire to rebuild as quickly as possible.

- Survivor remained married despite lack of emotional intimacy.
- Parent is detached/unable to be attuned to developmental needs of child.
- Emotions of parents transmitted to child.
- Obsessive retelling or silence of survivor's story.

Unique Challenges of Caregivers Who Inherit Trauma

- Child has inner struggle - maintain ties with parents past; strive to live their own lives.
- Children strive to protect parents.
- Children expected to be super achievers; carry burden of being replacement for lost family.
- Role Reversal - As survivors age, children become caregivers
 - Feelings of anger/resentment by children
 - Guilt and obligation to care for parents

Coping Techniques with Secondary Trauma

- RESILIENCE, like trauma can be transmitted across generations.
- Holocaust survivors and children have a tendency to be **task-oriented, hard workers, actively cope, adapt to challenges, strong family values.**
- As a result, grandchildren have an interest in social justice, greater awareness toward issues like immigration and Darfur.



How Older Adult Trauma Affects Care

Early life trauma can complicate common caregiver tasks and amplify stress.

- Showering
- Using public restrooms or waiting in line
- Physicians and invasive medical procedures, i.e. anesthesia, intravenous injections
- Hospitals, Relocation to skilled nursing facility
- Fear of aging process and death.

Activities can trigger memories of past trauma.

- Memories of gas chamber, result in anxiety, fear and refusal of care.
- Reminiscent of injections given for death; doctors in position of authority re: death.
- Lack of control/privacy vulnerability; powerlessness by decision making process
- Remember dehumanized deaths from past.

PCTI Care to Family Caregivers of Older Adults who are Victims of Trauma

- PCTI framework with caregivers - professional staff must be **sensitive to culture** and experience and **work collaboratively**.
- Equally important to address **needs of staff** to improve their knowledge and interaction with survivors as well as others who have experienced trauma, i.e. Staff Training
- Next slides will focus on **Promising Practices**, must preface by acknowledging the support from Holocaust Team—Alyssa Reiner and Greg Yucht – SW and Kathleen McMahon, Nurse.

Promising Practices

- JFSCNJ supports needs of caregivers through programs and other supportive resources:

Chronological Order inception of JFNA Grant

- Home Visits – collaboration with both SW (Russian Speaking) and nurse who met with new survivors(Id) and caregivers. Identified survivors from FSU. Caregiver concerns focused on stress, finances and sleep.

Promising Practices

- Caregiver Conferences
 - Meeting Challenges of Family Caregiving
Dr. Irit Felson
 - Finding Meaning in Family Caregiving – Drs. Barry Jacobs and Julia Mayer
 - Caring for a Loved One While Being Mindful of Your Own Needs – Jennifer Rutberg, Family Caregiver Program Specialist

First two conferences had breakout sessions on Alzheimer's/brain health, caring for Holocaust survivors, Mindfulness/Meditation, Physical Aspects of Self Care – Sleep, Nutrition, Exercise

Promising Practices

- Formation of Caregiver Advisory Board
 - Composition – caregivers of survivors, community members and professionals.
 - Convene monthly or every other month; review activities of department and ask their input in moving forward, i.e. workshop ideas, programs for grant.
 - Establish leadership of Advisory Committee

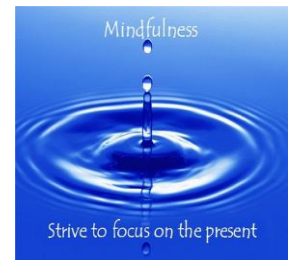


Promising Practices

- Caregiver Support Groups – convened support groups early on; learned that this is not the right direction for our constituency.
- Transitioned Support Groups to Psycho-educational workshops on self care.

Topics include:

- **Mindfulness and Meditation**
- **Yoga**
- **Painting**
- **Cooking**
- **Stress Reduction through Guided Imagery & Self Hypnosis**
- **Sleep**



Applications to Other Populations Experiencing Trauma

- Assistance with transition programs, i.e. new immigrants, prisoners--enabling people to feel secure. Similar to HIAS with Holocaust and JFS with Soviet Jews.
- Interviews – First hand, one on one interviews
- Socialization programs – develop networks
- Develop self-care techniques, i.e. meditation
- Important to have infrastructure in place—seamless transition of services can be provided.

Trauma Applied to Other Groups

- Ethnic cleansing in Bosnia
- Syrian Refugees
- Immigration – Dreamers
- Inactivity/retirement – generate more time to re-kindle past.
- Black Lives Matter
- Sexual violence

Resources

- Self Care Newsletters
- First Responder's Brochure
- Articles on Caregiving for local Jewish Papers
- Contact information for Conference Speakers
- Website <http://www.jfscentralnj.org>
- One on One Home Visits to Caregiver with Nurse and SW – helped self id as role of Caregiver

Questions



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For JFNA Alpha and Bravo Subgrantees

The password to prove participation in this webinar is:

CARE