INTERVENTIONS TO SUPPORT CAREGIVERS OR FAMILIES OF PATIENTS WITH TBI, PTSD, OR POLYTRAUMA:
A SYSTEMATIC REVIEW

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Full-length report available on ESP website:
http://www.hsrda.research.va.gov/publications/esp/reports.cfm
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Background

- 39.8 million caregivers
- 1.1 million caregivers of US Veterans

*Coughlin, 2017 Ramchard, 2014
Family Caregiver Alliance, 2017*
Background

- 39.8 million caregivers
- 1.1 million caregivers of US Veterans
- Caregiving not temporary
- Negative outcomes for caregiver
  - QoL, economic outcomes, caregiver burden

Coughlin, 2017 Ramchard, 2014
Family Caregiver Alliance, 2017

Evidence-based Synthesis Program (ESP)
Background

• “Any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition”

• Some family members do not identify as “caregiver”
National VA efforts to involve family members

- Marital and family counseling must be offered
- Family-involved interventions being tested and disseminated
  - National dissemination of evidenced-based practices (EBP) for family-involved mental health therapies
  - SAFE, REACH, NAMI Homefront, VA-CRAFT, Coaching into Care, Hi-Fives, REORDER, and others
- Program for Comprehensive Assistance of Family Caregivers (PCAFC)

The Program for Comprehensive Assistance of Family Caregivers (PCAFC) targets family caregivers of...

A. VA users with qualifying service related injury
B. VA users with qualifying medical condition
C. Post-9/11 VA users with qualifying service related injury
D. Post-9/11 VA users with qualifying medical condition
Audience Poll Question

The Program for Comprehensive Assistance of Family Caregivers (PCAFC) targets family caregivers of...

A. VA users with qualifying service related injury
B. VA users with qualifying medical condition
C. **Post-9/11 VA users with qualifying service related injury**
D. Post-9/11 VA users with qualifying medical condition
National VA efforts to involve family members

- Program for Comprehensive Assistance of Family Caregivers (PCAFC)

https://www.caregiver.va.gov/support/support_benefits.asp
Program for Comprehensive Assistance of Family Caregivers (PCAFC)

PCAFC-Description
- Implemented at every VAMC
- Support for family caregivers of eligible post-9/11 Veterans
- Require 6 months+ care due to service-related injuries

Services
- Monthly stipend (range $600-2,300)
- Travel
- Health insurance
- Mental health services
- Respite care
Program for Comprehensive Assistance of Family Caregivers (PCAFC)

- As of 10/2017 program has served over 33,000 caregivers
- Financial outlays of over 1 billion
Rationale for review

- Effectiveness interventions unclear
- Reviews limited to recipients with cognitive or memory disorders or chronic medical illnesses such as cancer
- Existing evidence demonstrates:
  - Reduce caregiver burden and distress
  - Improve care recipient function
- Report commissioned by the Caregiver Support Program and the Office of Mental Health and Suicide Prevention

Interventions to Support Caregivers or Families of Patients with TBI, PTSD, or Polytrauma: A Systematic Review

July 2017

Purpose of this report

This evidence synthesis describes the volume of published literature and the effects of family caregiving support programs for patients with

• traumatic brain injury (TBI)
• posttraumatic stress disorder (PTSD)
• polytrauma
For an intervention focused on supporting a family-member of patients with PTSD, would you expect to see an improvement in:

A. Psychological symptoms for the patient
B. Psychological symptoms/burden for the caregiver
C. Both
Audience Poll Question

For an intervention focused on supporting a family-member of patients with PTSD, would you expect to see an improvement in:

A. **Psychological symptoms for the patient**
B. Psychological symptoms/burden for the caregiver
C. Both
**Standard Systematic Review Methods**

**Literature search & study selection**
- PubMed, CINAHL PsychInfo
- Pre-specified eligibility criteria
- Identify eligible studies

**Data abstraction & quality**
- Abstracted data elements
- Rated study quality
- Data described and synthesized qualitatively
- Meta-analysis where feasible; sensitivity analyses
- Strength of evidence
Eligibility criteria

**Population**
- Adults with TBI, PTSD or polytrauma
- Caregivers have a pre-existing relationship with the patient

**Comparators** – inactive or active
**Setting** – community, in-home
**Design** – RCT, non-RCT, controlled before & after, interrupted time series
**English** language
**1995** forward
Eligible intervention components

- Financial Assistance
- Illness education
- Support in the home setting
- Information
- Therapy
- Practical support
- Training
Eligible outcomes

Care recipient outcomes
- Functional status, HQoL, utilization
- Disease-specific & psychological sx
- Adverse effects

Caregiver Outcomes
- Caregiver burden
- Psychological sx
- Adverse effects

Household Outcomes
- Household economic status
- Family function
Results: literature flow

- 2912 unique citations → 19 eligible papers representing 13 unique studies
  - 10 randomized trials
  - 2 nonrandomized trials
  - 1 interrupted time series
- 10 conducted in US
- Clinical trials.gov:
  - 14 relevant ongoing studies
  - Interventions similar to those in published literature
  - No evidence of publication bias
Description of volume of literature

- No studies enrolled patients assessed to have polytrauma
- 9 studies enrolled patients assessed to have TBI
  - 1 study with Veteran patients
- 4 studies enrolled patients assessed to have PTSD
  - 3 studies with Veteran patients
- Other gaps
  - Financial assistance interventions not examined
  - Adverse effects and household economic status outcomes not reported
## Evidence Profile for Family Caregiving Studies

<table>
<thead>
<tr>
<th></th>
<th>TBI Studies (n=9)</th>
<th>PTSD Studies (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study designs</strong></td>
<td>6 randomized</td>
<td>4 randomized</td>
</tr>
<tr>
<td><strong>Study years</strong></td>
<td>1995-2016</td>
<td>1999-2015</td>
</tr>
<tr>
<td><strong>Number of patients</strong></td>
<td>1,148</td>
<td>324</td>
</tr>
<tr>
<td><strong>Number of caregivers</strong></td>
<td>673</td>
<td>97</td>
</tr>
<tr>
<td><strong>Mean patient age</strong></td>
<td>38.7</td>
<td>38.0</td>
</tr>
<tr>
<td><strong>Mean caregiver age</strong></td>
<td>48.6</td>
<td>34.5</td>
</tr>
</tbody>
</table>
Frequency of studies reporting outcomes by caregiver, care recipient, or household level.
Presentation of results for TBI

- Meta-analysis
  - Care recipient
  - Caregiver
  - Strength of evidence
- Qualitative
  - Care recipient
  - Caregiver
  - Household

Outcomes captured by number of studies

- Functional status
- Emotional functional status
- Psychological symptoms
- TBI symptoms
- Quality of life
- Burden

Number of studies

VETERANS HEALTH ADMINISTRATION
Effects in TBI from meta-analysis

- Care recipient outcomes
  - Overall functional status
  - Physical functional status
  - Emotional/social functional status
  - Psychological symptoms

- Caregiver Outcomes
  - Psychological symptoms

- Household Outcomes
  - None
Effects in TBI from meta-analysis

- Overall functional status: 0.29 [-0.51 to 1.08]
- Physical functional status: 0.14 [-0.31 to 0.59]
- Emotional functional status: 0.01 [-0.45 to 0.48]
- Psychological symptoms: -0.25 [-0.62 to 0.12]
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- Psychological symptoms: -0.25 [-0.62 to 0.12]
## Strength of evidence: TBI Care Recipients

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Number of RCTs (Patients)</th>
<th>Findings</th>
<th>Strength of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall functional status</td>
<td>3 (238)</td>
<td>SMD 0.29 higher (0.51 lower to 1.08 higher)</td>
<td>Low</td>
</tr>
<tr>
<td>Physical functional status</td>
<td>3 (238)</td>
<td>SMD 0.14 higher (0.31 lower to 0.59 higher)</td>
<td>Low</td>
</tr>
<tr>
<td>Mental functional status</td>
<td>3 (238)</td>
<td>SMD 0.42 higher (0.68 lower to 1.51 higher)</td>
<td>Very Low</td>
</tr>
<tr>
<td>Psychological symptoms</td>
<td>3 (293)</td>
<td>SMD 0.25 lower (0.62 lower to 0.12 higher)</td>
<td>Low</td>
</tr>
</tbody>
</table>
Effects in TBI from meta-analysis

- Psychological symptoms

Caregiver Outcomes
Effects in TBI from meta-analysis

Forest Plot of Psychological Symptoms for TBI Caregivers

<table>
<thead>
<tr>
<th>Study</th>
<th>Intervention</th>
<th>Control</th>
<th>Weight</th>
<th>SMD [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rivera 2008</td>
<td>17.80 13.10 33</td>
<td>20.70 12.24 34</td>
<td>26.6%</td>
<td>-0.23 [-0.71, 0.25]</td>
</tr>
<tr>
<td>Powell 2016</td>
<td>45.30 11.00 59</td>
<td>49.90 11.30 65</td>
<td>48.5%</td>
<td>-0.41 [-0.77, -0.05]</td>
</tr>
<tr>
<td>Winter 2016</td>
<td>9.03 6.46 29</td>
<td>10.74 7.40 34</td>
<td>24.9%</td>
<td>-0.24 [-0.74, 0.26]</td>
</tr>
<tr>
<td>Summary (I² = 0.0%, Q = 0.5, P=0.78)</td>
<td></td>
<td></td>
<td>100%</td>
<td>-0.32 [-0.59, -0.05]</td>
</tr>
</tbody>
</table>
## Strength of evidence TBI caregiver outcomes

<table>
<thead>
<tr>
<th>Outcome</th>
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<th>Findings</th>
<th>Strength of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological symptoms</td>
<td>3 (296)</td>
<td>SMD 0.32 lower(^a) (0.59 lower to 0.05 lower)</td>
<td>Low</td>
</tr>
</tbody>
</table>
| Caregiver burden              | 3 (252)                   | Median effect size 0.31 (range 0.30 to 0.35) 
\(p=NS\) for 2 of 3 studies | Low                  |
Effects in TBI from qualitative analysis

- **Potential benefit** for TBI symptoms and QoL
- **Small benefit** for TBI caregiver burden
- **Inadequate data** on adverse events and household economic status
A Test of Behavioral Family Therapy to Augment Exposure for Combat-Related Posttraumatic Stress Disorder

EVALUATING A MULTIPLE-FAMILY GROUP ACCESS INTERVENTION FOR REFUGEES WITH PTSD
Weine et al. J Marital Fam Ther. 2008 Apr;34(2):149-64

Effect of Cognitive-Behavioral Couple Therapy for PTSD
A Randomized Controlled Trial
Monson et al. JAMA. 2012;308(7):700-709

Efficacy of Structured Approach Therapy in Reducing PTSD in Returning Veterans: A Randomized Clinical Trial
Sautter et al. Psychol Serv. 2015;12(3):199-212
Presentation of results for PTSD

- Meta-analysis
  - None
- Qualitative
  - Care recipient
  - Caregiver
  - Household
  - SOE

Outcomes captured by number of studies

- Care Recipient PTSD: 4 studies
- Care Recipient psychological: 4 studies
- Caregiver psychological: 2 studies
- Family relationship: 2 studies
- Mental Health visits: 1 study
### Effects in PTSD from qualitative analysis

<table>
<thead>
<tr>
<th>Care recipient outcomes</th>
<th>Caregiver Outcomes</th>
<th>Household Outcomes</th>
</tr>
</thead>
</table>
| • Couples therapy – improvement in PTSD & other psychological symptoms  
• Increase in mental health visits (preliminary)  
• Improvement in relational functioning (patient-reported) | • Possible improvement in psychological symptoms (preliminary)  
• No improvement in interpersonal relationships | • Not examined. |
### Strength of evidence PTSD patient outcomes

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Number of RCTs (Patients)</th>
<th>Findings</th>
<th>Strength of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>PTSD symptoms</td>
<td>2 (97)</td>
<td>Clinically improved symptoms by clinician interview (range 23.2 to 27.6)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Interpersonal relationships</td>
<td>2 (97)</td>
<td>Improved as reported by the patient but not the caregiver</td>
<td>Low</td>
</tr>
</tbody>
</table>
Discussion

- Existing literature is small (n=9 TBI; n=4 PTSD)
- Most commonly used intervention component was illness education
- Intervention goals included:
  - reduce caregiver burden
  - enhance family function
  - improve clinical care and home environment
  - improve condition-specific symptoms
  - increase family knowledge of health care resources
- Mixed pattern of intervention effects on caregiver and patient outcomes, direction of effects favored intervention
- Strength of evidence generally low
Applicability to VA

• Studies that included Veteran samples
  – PTSD: 3 out of 4
  – TBI: 1 out of 9

• In most studies, TBIs sustained in noncombat situations

• Existing literature does not address all key tenants of PCAFC (e.g. stipend)
Comprehensive Support for Family Caregivers: Impact on Veteran Health Care Utilization and Costs

Courtney Harold Van Houtven¹,², Valerie A. Smith¹,², Karen M. Stechuchak¹, Megan Shepherd-Banigan¹, Susan Nicole Hastings¹,²,³, Matthew L. Maciejewski¹,², Gilbert Darryl Wieland¹, Maren K. Olsen¹,³, Katherine E. M. Miller¹, Margaret Kabat⁴, Jennifer Henius⁴, Margaret Campbell-Kotler⁴, and Eugene Z. Oddone¹,²
Limitations

• No evidence for patients with polytrauma, sparse evidence for patients with PTSD
• No evidence on financial support
• Uncertainty about relationship between outcomes and intervention dose, mode of delivery, and components
• Outcome measures varied
• High heterogeneity
Highest priority research gaps

• Build evidence about patients with polytrauma, PTSD
• Rigorous study designs
• Studies to examine financial assistance
• Intervention development should be informed by conceptual models (i.e. stress-vulnerability model)
• Need to use consistent measures across studies to allow for cross-study comparability
• Minimal use of patient reported outcomes
Conclusions

• Small but growing literature
• Evidence is inconclusive
• Yet, promising trends for interventions on caregiver burden and psychological symptoms and patient condition-specific symptoms
Discussant: Margaret Kabat, LCSW-C, National Director, VA Caregiver Support Program

For more information:
https://www.caregiver.va.gov/support/support_benefits.asp
Questions?

If you have further questions, please feel free to contact:

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Full-length report and cyberseminar available on ESP website:
http://www.hsrd.research.va.gov/publications/esp/