

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.hsrd.research.va.gov/publications/esp/reports.cfm>

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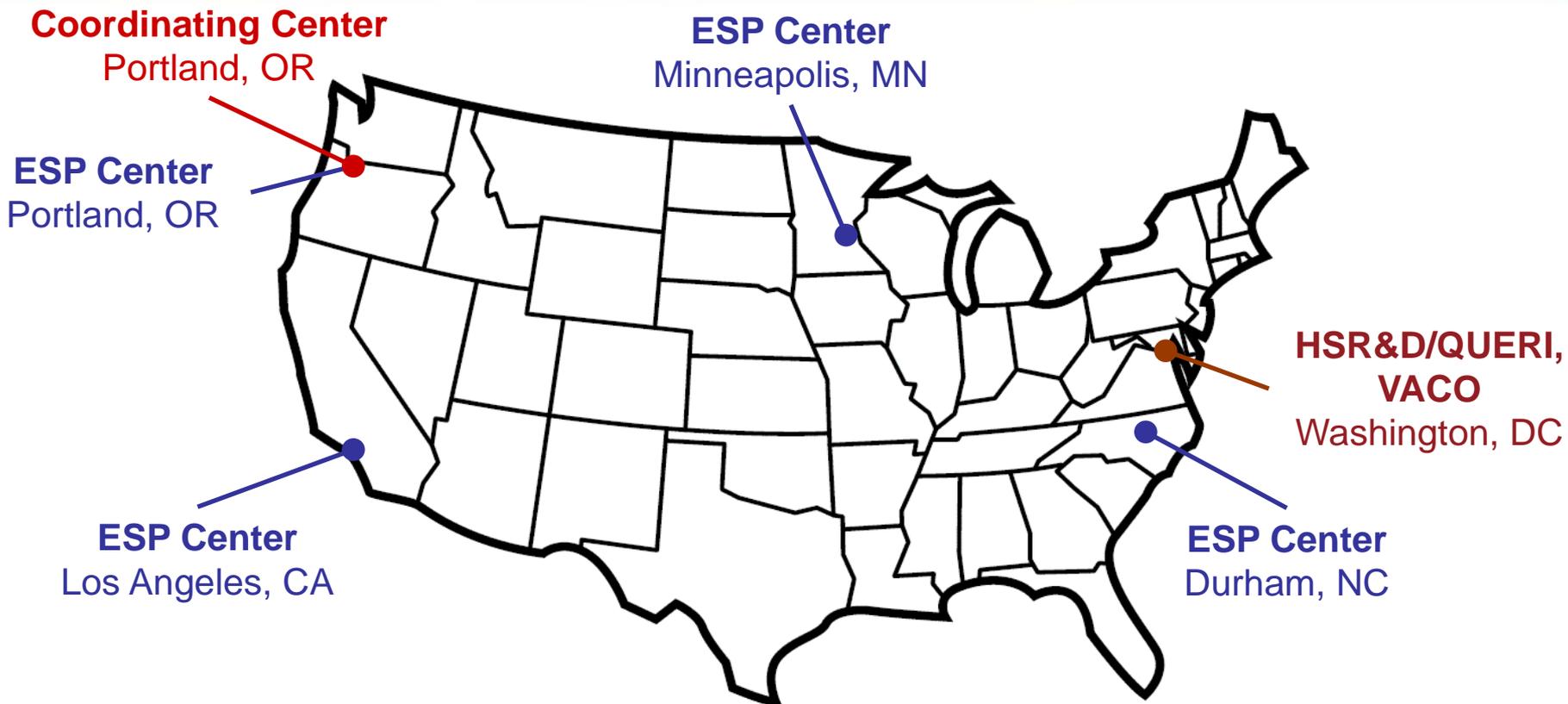
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ESP Center Locations



<http://www.hsrd.research.va.gov/publications/esp/TopicNominationForm.pdf>

Background

- **39.8 million** caregivers
- **1.1 million** caregivers of US Veterans

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

Background



Caregiving Around the Clock

CaregiverAction.org

- 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*

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)

Makin-Byrd 2011, Glynn 2013, Fischer 2013, Dixon 2011, Dixon 2014, Swinkles 2017, Erbes 2016, Sherman 2012, Van Houtven 2017

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

Audience Poll Question

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

- A. VA users with qualifying service related injury
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- 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

Department of Veterans Affairs
Health Services Research & Development Service

Evidence-based Synthesis Program

NOTE: This report is embargoed pending journal publication. It is for internal use by the Department of Veterans Affairs and should not be distributed outside the agency. Once published, a final report will be available on the ESP public website.

QUERI

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

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

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

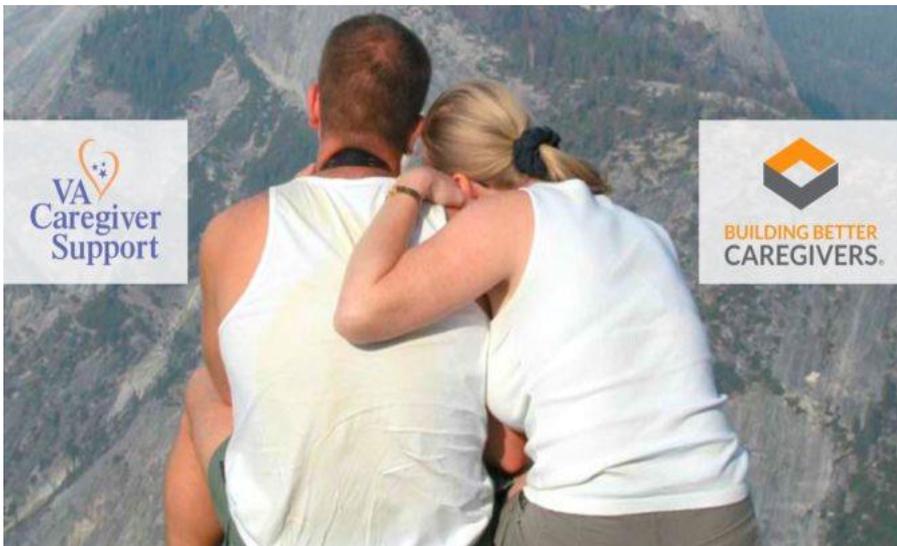
- Abstracted data elements
- Rated study quality
- Data described and synthesized qualitatively
- Meta-analysis where feasible; sensitivity analyses
- Strength of evidence

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



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

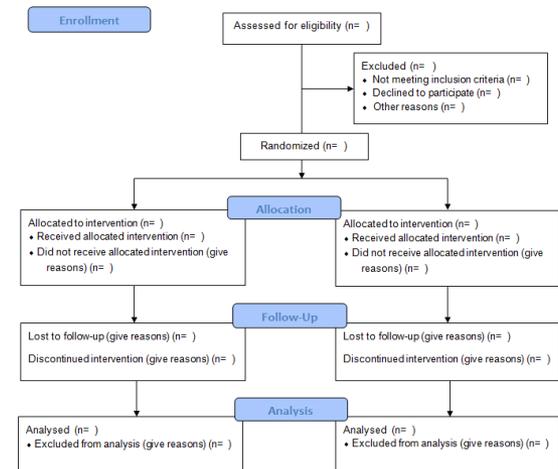
- **Household economic status**
- **Family function**

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



CONSORT 2010 Flow Diagram



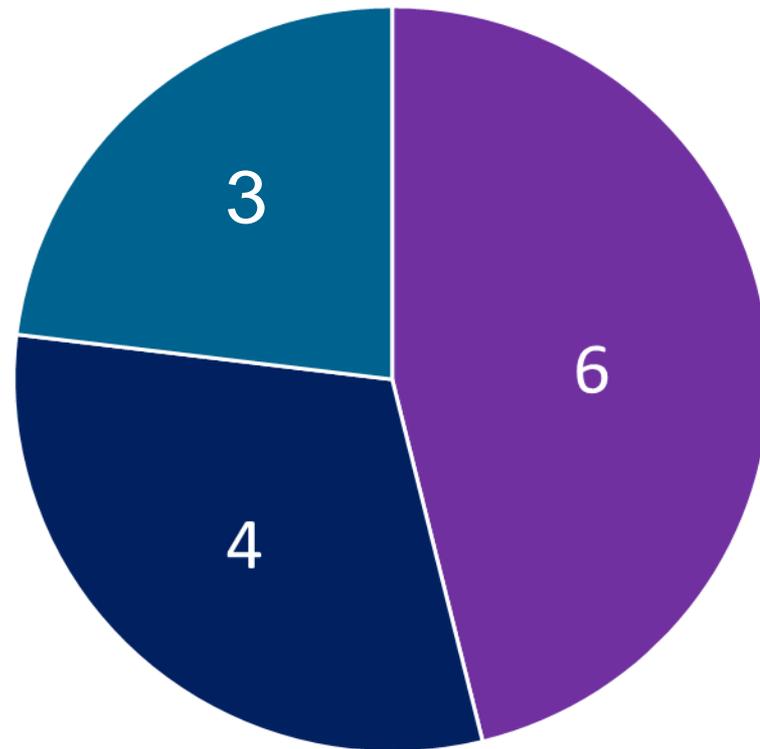
Description of volume of literature

- 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

	TBI Studies (n=9)	PTSD Studies (n=4)
Study designs	6 randomized	4 randomized
Study years	1995-2016	1999-2015
Number of patients	1,148	324
Number of caregivers	673	97
Mean patient age	38.7	38.0
Mean caregiver age	48.6	34.5

Frequency of studies reporting outcomes by caregiver, care recipient, or household level



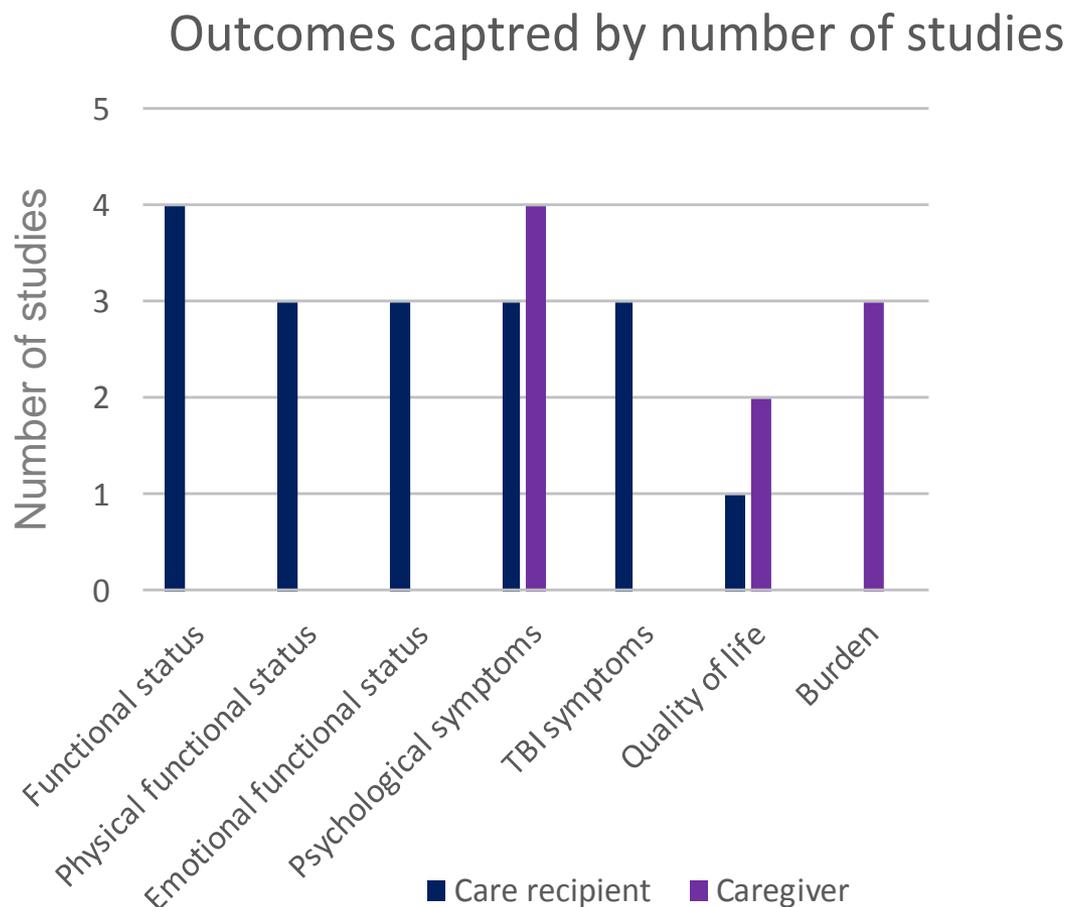
■ Caregiver

■ Care recipient

■ Household

Presentation of results for TBI

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



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

Care recipient outcomes

- 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]

Effects in TBI from meta-analysis

Care recipient outcomes

- Overall functional status 0.29 [-0.51 to 1.08]
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Effects in TBI from meta-analysis

Care recipient outcomes

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- Psychological symptoms -0.25 [-0.62 to 0.12]

Strength of evidence: TBI Care Recipients

Outcome	Number of RCTs (Patients)	Findings	Strength of Evidence
Overall functional status	3 (238)	SMD 0.29 higher (0.51 lower to 1.08 higher)	Low
Physical functional status	3 (238)	SMD 0.14 higher (0.31 lower to 0.59 higher)	Low
Mental functional status	3 (238)	SMD 0.42 higher (0.68 lower to 1.51 higher)	Very Low
Psychological symptoms	3 (293)	SMD 0.25 lower (0.62 lower to 0.12 higher)	Low

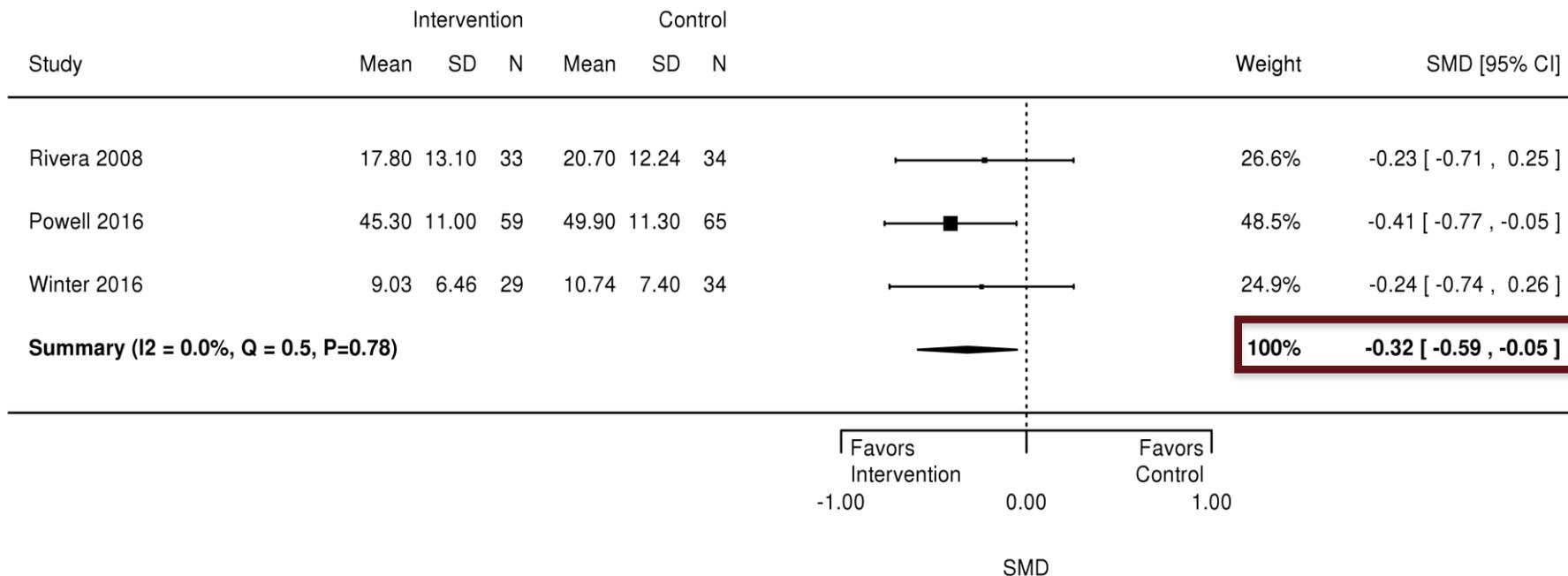
Effects in TBI from meta-analysis

Caregiver Outcomes

- Psychological symptoms

Effects in TBI from meta-analysis

Forest Plot of Psychological Symptoms for TBI Caregivers



Strength of evidence TBI caregiver outcomes

Outcome	Number of RCTs (Patients)	Findings	Strength of Evidence
Psychological symptoms	3 (296)	SMD 0.32 lower ^a (0.59 lower to 0.05 lower)	Low
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

Care
recipient
outcomes

- **Potential benefit** for TBI symptoms and QoL

Caregiver
Outcomes

- **Small benefit** for TBI caregiver burden

Household
Outcomes

- **Inadequate data** on *adverse events* and *household economic status*



A Test of Behavioral Family Therapy to Augment Exposure for Combat-Related Posttraumatic Stress Disorder

Glynn et al. Journal of Consulting and Clinical Psychology 1999, Vol. 67, No. 2, 243-251



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



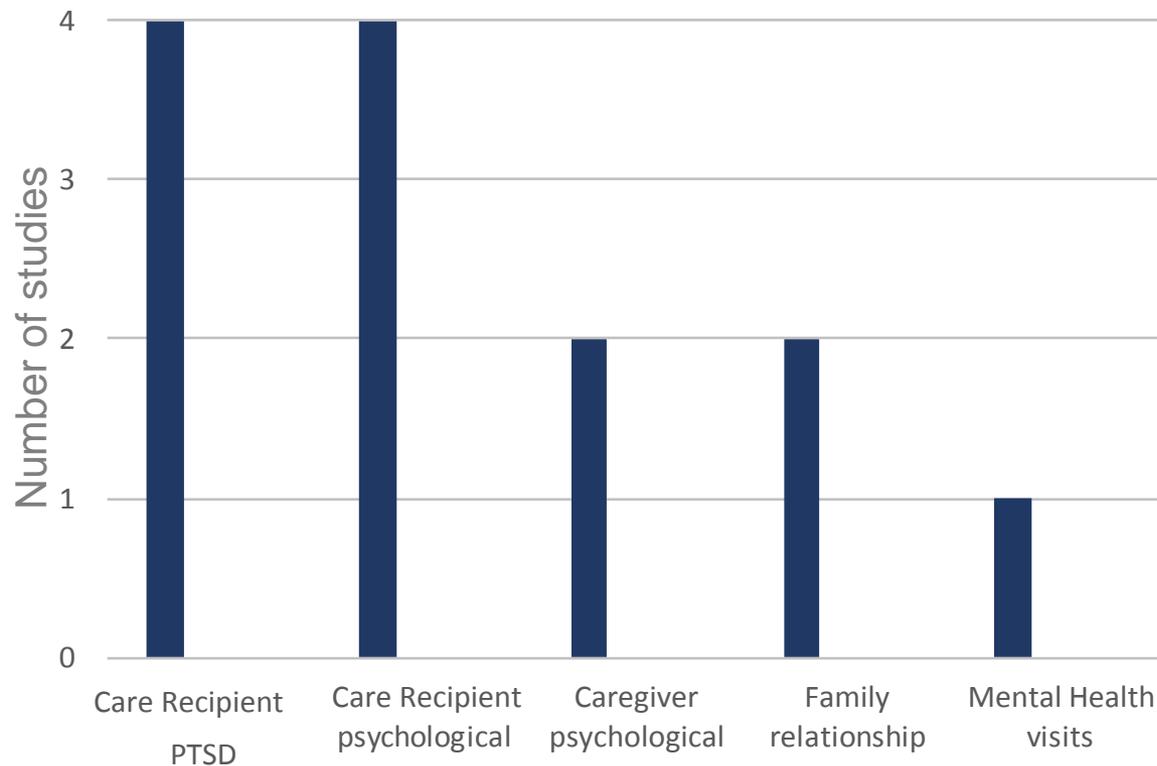
Efficacy of Structured Approach Therapy in Reducing PTSD in Returning Veterans: A Randomized Clinical Trial

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



Effects in PTSD from qualitative analysis

Care recipient outcomes

- Couples therapy – improvement in PTSD & other psychological symptoms
- Increase in mental health visits (preliminary)
- Improvement in relational functioning (patient-reported)

Caregiver Outcomes

- Possible improvement in psychological symptoms (preliminary)
- No improvement in interpersonal relationships

Household Outcomes

- Not examined.

Strength of evidence PTSD patient outcomes

Outcome	Number of RCTs (Patients)	Findings	Strength of Evidence
PTSD symptoms	2 (97)	Clinically improved symptoms by clinician interview (range 23.2 to 27.6) ^b and patient report	Moderate
Interpersonal relationships	2 (97)	Improved as reported by the patient but not the caregiver	Low

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

Medical Care Research and Review

1-27

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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/>