



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

February 2018

Prepared for:

Department of Veterans Affairs
Veterans Health Administration
Quality Enhancement Research Initiative
Health Services Research & Development Service
Washington, DC 20420

Prepared by:

Evidence-based Synthesis Program (ESP) Center
Durham Veterans Affairs Healthcare System
Durham, NC
John W. Williams Jr., MD, MHSc, Director

Investigators:

Co-Investigators:

Megan E. Shepherd-Banigan, PhD, MPH
Jennifer R. McDuffie, PhD
Abigail Shapiro, PhD
Mira Brancu, PhD
Nina Sperber, PhD
Neha N. Mehta, MD
Courtney H. van Houtven, PhD
John W. Williams Jr, MD, MHSc

Research Associate:

Avishek Nagi, MS

Medical Editor:

Liz Wing, MA



PREFACE

The VA Evidence-based Synthesis Program (ESP) was established in 2007 to provide timely and accurate syntheses of targeted health care topics of particular importance to clinicians, managers, and policymakers as they work to improve the health and health care of Veterans. QUERI provides funding for four ESP Centers, and each Center has an active University affiliation. Center Directors are recognized leaders in the field of evidence synthesis with close ties to the AHRQ Evidence-based Practice Centers. The ESP is governed by a Steering Committee comprised of participants from VHA Policy, Program, and Operations Offices, VISN leadership, field-based investigators, and others as designated appropriate by QUERI/HSR&D.

The ESP Centers generate evidence syntheses on important clinical practice topics. These reports help:

- Develop clinical policies informed by evidence;
- Implement effective services to improve patient outcomes and to support VA clinical practice guidelines and performance measures; and
- Set the direction for future research to address gaps in clinical knowledge.

The ESP disseminates these reports throughout VA and in the published literature; some evidence syntheses have informed the clinical guidelines of large professional organizations.

The ESP Coordinating Center (ESP CC), located in Portland, Oregon, was created in 2009 to expand the capacity of QUERI/HSR&D and is charged with oversight of national ESP program operations, program development and evaluation, and dissemination efforts. The ESP CC establishes standard operating procedures for the production of evidence synthesis reports; facilitates a national topic nomination, prioritization, and selection process; manages the research portfolio of each Center; facilitates editorial review processes; ensures methodological consistency and quality of products; produces “rapid response evidence briefs” at the request of VHA senior leadership; collaborates with HSR&D Center for Information Dissemination and Education Resources (CIDER) to develop a national dissemination strategy for all ESP products; and interfaces with stakeholders to effectively engage the program.

Comments on this evidence report are welcome and can be sent to Nicole Floyd, ESP CC Program Manager, at Nicole.Floyd@va.gov.

Recommended citation: Shepherd-Banigan ME, McDuffie JR, Shapiro A, Brancu M, Sperber N, Mehta NN, van Houtven CH, Williams JW Jr. Interventions to Support Caregivers or Families of Patients with TBI, PTSD, or Polytrauma: A Systematic Review. VA ESP Project #09-009; 2018.

This report is based on research conducted by the Evidence-based Synthesis Program (ESP) Center located at the **Durham VA Medical Center, Durham, NC**, funded by the Department of Veterans Affairs, Veterans Health Administration, Office of Research and Development, Quality Enhancement Research Initiative. The findings and conclusions in this document are those of the author(s) who are responsible for its contents; the findings and conclusions do not necessarily represent the views of the Department of Veterans Affairs or the United States government. Therefore, no statement in this article should be construed as an official position of the Department of Veterans Affairs. No investigators have any affiliations or financial involvement (eg, employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties) that conflict with material presented in the report.

STAKEHOLDERS AND TECHNICAL EXPERT PANEL

In designing the study questions and methodology at the outset of this report, the ESP consulted several technical and content experts. Broad expertise and perspectives were sought. Divergent and conflicting opinions are common and perceived as healthy scientific discourse that results in a thoughtful, relevant systematic review. Therefore, in the end, study questions, design, methodologic approaches, and/or conclusions do not necessarily represent the views of individual technical and content experts.

The list of stakeholders and members of the Technical Expert Panel (TEP) who provided input to this report follows.

Stakeholders

Margaret Kabat, LCSW-C
National Director
VA Caregiver Support Program

Shirley Glynn, PhD
Program Manager
VA National Family Services Evidence-Based Clinical Training Program

Technical Expert Panel

Josephine (Jo) Jacobs, PhD
Health Economist
Health Economics Resource Center

Joel Scholten, MD
Associate Chief of Staff for Rehabilitation Services

Ranak Trivedi, PhD
Research Health Science Specialist
Center for Innovation to Implementation

CORRIGENDUM

In this updated report (February 13, 2018), we made the following changes:

1. Correctly attributed the findings on caregiver burden to Moriarty et al 2016 instead of Winter et al 2016. These publications reported results from the same study, but the findings about caregiver burden were published by Moriarty and colleagues.
2. As a result of study details published in Moriarty et al 2016, we updated the risk of bias of the overall study from unclear to low. This contributed to a change in the strength of evidence from low to moderate for the meta-analyses that included results published by Winter et al 2016: overall patient function, physical function, and caregiver psychological symptoms. These strength of evidence ratings have been updated.
3. We added Hanks et al 2012 to the meta-analysis for patient physical function after realizing that it had been erroneously omitted; we have updated the results from that meta-analysis throughout the report.

EXECUTIVE SUMMARY

INTRODUCTION

Family members perform a significant service caring for Veterans with severe physical, mental, and cognitive impairments. A family caregiver may be defined as “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.” Depending on the injuries and health conditions, for some families, the need for intensive family caregiving support can last for decades. Further, caregiving can have negative implications for the caregiver’s physical and mental health, employment, and financial security.

Other systematic reviews have shown that some caregiver supportive services can reduce caregiver burden and mental distress and improve care recipient function; however, this research has focused most frequently on recipients with cognitive or memory disorders and illnesses such as cancer. There is a need to better understand the impact of interventions that support caregivers or families of patients with disabling conditions common among Veterans. This evidence synthesis describes the volume of published literature evaluating the effects of family caregiving support programs for patients with traumatic brain injury (TBI), posttraumatic stress disorder (PTSD), or polytrauma.

The Key Questions (KQs) were:

KQ 1: For which patient groups (*ie*, patients with posttraumatic stress disorder, traumatic brain injury, or polytrauma) that receive interventions that involve family members has the impact on care recipient outcomes been assessed?

KQ 2: What effects do programs or strategies that involve family caregivers have on care recipient and caregiver outcomes? Outcomes of interest include caregiver burden and psychological symptoms; care recipient functional status, psychological symptoms, quality-of-life indicators, disease-specific symptoms, independence, health care utilization; and family economic status, family functioning, and clinical eligibility for specific programs or services.

METHODS

Data Sources and Searches

We conducted searches of MEDLINE® (via PubMed), CINAHL, and PsycINFO through December 19, 2016. We evaluated the bibliographies of recent reviews and contacted content experts to identify additional relevant studies.

Study Selection

Using prespecified eligibility criteria, titles and abstracts of identified articles were reviewed independently by 2 reviewers for relevance to the KQs. At the full-text review stage, reviewers were required to agree on inclusion for data abstraction. In brief, we included randomized trials and quasi-experimental studies conducted with patients having TBI, PTSD, or polytrauma that evaluated interventions designed to support the caregiver or family member, or designed to support the patient with involvement or support from the family member (*eg*, couples therapy).

For the purposes of this report, we use the term “family caregiving interventions” to mean interventions that are either patient- or caregiver-focused and involve caregivers or families of patients (care recipients) with TBI, PTSD, or polytrauma. We also use the term “caregivers” to refer to persons who either provide unpaid hands-on help or help navigate the health care system.

Data Abstraction and Quality Assessment

Abstracted elements included patient descriptors, caregiver characteristics, intervention characteristics/exposure details, comparators, outcomes of interest, descriptors to assess applicability, and quality elements. We abstracted outcomes at end of treatment and for the longest follow-up period reported. Our general framework included 5 major categories: (1) skills training for caregivers, (2) education for caregivers, (3) interventions that provide support or counseling related to the caregiving role, (4) interventions to enhance support for caregivers, and (5) unique interventions with unique intervention targets.

We used the key quality criteria described by the Cochrane Effective Practice and Organization of Care (EPOC) Review Group for RCTs and nonrandomized studies that meet EPOC criteria. We assigned a summary risk of bias score (low, unclear, or high) to individual studies.

Data Synthesis and Analysis

For KQ 1, we described the breadth and types of studies conducted. For KQ 2, summary tables describe the key study characteristics of the included studies such as study design, patient demographics, and details of the intervention and comparator. We then determined the feasibility of completing a quantitative synthesis (*ie*, meta-analysis) to estimate summary effects. Continuous outcomes were summarized using the standardized mean difference because studies used different measures for the same construct. Sensitivity analyses omitted studies judged high risk of bias. We evaluated for statistical heterogeneity using visual inspection and Cochran’s Q and I^2 statistics. When quantitative synthesis was not feasible, we analyzed the data qualitatively. We gave more weight to the evidence from higher-quality studies with more precise estimates of effect. The strength of evidence for each key question was assessed using the approach described in the Agency for Healthcare Research and Quality’s *Methods Guide*.

RESULTS

Results of Literature Search

The literature search identified 2837 unique citations from a combined search of MEDLINE (via PubMed (n=1319)), PsycINFO (n=149), and CINAHL (n=1369). An additional 75 articles were identified from manual searches of bibliographies and current literature published after the search date, for a total of 2912 unique citations. After screening at both the abstract and full-text level, 19 articles were retained for data abstraction (13 primary papers and 6 companion papers).

Summary of Results for Key Questions

We identified 13 studies that evaluated family caregiving interventions of patients with TBI (n=9) or PTSD (n=4). We did not identify any studies that enrolled patients assessed to have polytrauma. Of these studies, 10 were randomized controlled trials (RCTs), 2 were nonrandomized trials, and 1 was an interrupted time series design. Except for the interrupted times series study, interventions were compared with waitlist or inactive comparators in 5

studies, usual care in 4, and active comparators in 4. Most studies were conducted in the United States (n=10), and 4 included Veterans. All 13 primary studies were applicable to both KQs.

KQ 1: The intervention target was both caregiver and care recipient in 6 studies, only the care recipient in 3 studies, and only the caregiver in 4 studies. The most commonly reported care recipient outcomes were physical or mental functional status and psychological status (*eg*, depression severity). Delivery was most often one-on-one (n=9). Eight different disciplines were used for the interventionist. The frequency and duration of the interventions varied greatly. The majority of interventions included illness education (n=12, 92%) and skills training (n=9, 69%). Other components were a type of therapy, social support, written materials, and help with resource navigation. There were no studies that offered financial assistance or other practical assistance, such as respite care, as part of the intervention. No studies reported on any type of adverse events or clinical eligibility for specific programs or services. A variety of measurement instruments were utilized for each outcome category. Timing of outcome measurement varied widely across studies.

KQ 2: Interventions that included family caregivers did not improve overall functional status, physical functional status, emotional/social functional status, or psychological symptoms for the *TBI care recipient*. However, these outcomes were reported in only a few studies, and the 95% confidence interval did not exclude a moderate effect (moderate to very low strength of evidence). Interventions that included family caregivers showed positive effects for psychological symptoms of the *TBI caregiver*. Qualitative synthesis demonstrated a consistent pattern of small beneficial effects of the interventions on *TBI caregiver burden*; however, only 1 of the 3 studies found a statistically significant effect of the intervention on caregiver burden.

Strength of Evidence for Effects of Family Caregiving Interventions in TBI

Outcome	Number of RCTs (Patients)	Findings	Strength of Evidence (Rationale by Domain)
<i>Care recipient outcomes</i>			
Overall functional status	3 (238)	SMD 0.29 higher (0.51 lower to 1.08 higher)	Moderate
Physical functional status	4 (334)	SMD 0.22 higher (0.11 lower to 0.55 higher)	Moderate
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
<i>Caregiver outcomes</i>			
Psychological symptoms	3 (296)	SMD 0.32 lower ^a (0.59 lower to 0.05 lower)	Moderate
Caregiver burden	3 (252)	Median effect size 0.31 (range 0.30 to 0.35)	Low

^a SMD and SOE rating reported are from the sensitivity analyses excluding the single high risk of bias study. Abbreviations: RCT=randomized controlled trial; SMD=standardized mean difference

Two forms of couples therapy for PTSD (cognitive behavioral conjoint therapy [CBCT-PTSD] and structured approach therapy [SAT]) showed consistent improvements in PTSD-related symptoms and some other psychological symptoms for *PTSD care recipients*; patient-reported, but not partner-reported, relationship quality improved (moderate strength of evidence). There is preliminary evidence from 1 study that caregiver involvement may improve mental health treatment-seeking and engagement for refugees with PTSD. The evidence is insufficient to determine if evidence-based treatment for PTSD, augmented by behavioral family therapy (BFT), improves *PTSD caregiver* or *care recipient* outcomes. However, one couples-based treatment for PTSD (CBCT-PTSD) found a significant positive effect of the intervention on psychological symptoms for partners who were in the distressed range at pretreatment.

Strength of Evidence for Effects of Family Caregiving Interventions in PTSD

Outcome	Number of RCTs (Couples)	Findings	Strength of Evidence (Rationale by Domain)
<i>Care recipient outcomes</i>			
PTSD symptoms	2 (97)	Clinically improved symptoms by clinician interview (range 23.2 to 27.6) ^a and patient report	Moderate
Interpersonal relationships	2 (97)	Improved as reported by the patient but not the caregiver	Low

^a Clinician-administered PTSD scale.

Abbreviations: RCT=randomized controlled trial; ROB=risk of bias

Care recipient independence, adverse effects, clinical eligibility for specific programs or services, and household economic status were not examined in any identified study. Only 2 TBI studies were judged low risk of bias, decreasing confidence in the estimates of intervention effects; no PTSD studies were judged low risk of bias. Strength of evidence for the meta-analyses for TBI ranged from very low (emotional/social functional status) to low (all others). Strength of evidence for couples-based therapies for PTSD ranged from low (interpersonal relationships) to moderate (PTSD symptoms).

DISCUSSION

Key Findings and Strength of Evidence

This is the first systematic review to examine family caregiver interventions for patients with TBI, PTSD, or polytrauma. As expected, the existing literature is small; 13 studies meeting the prespecified review criteria were identified. The majority of studies enrolled patients with TBI (n=9); no studies enrolled patients assessed to have polytrauma. The most commonly utilized intervention component was illness education. Other commonly used components included skills training, social support, and therapy. We found no interventions that provided financial assistance. While individual interventions varied in delivery type, delivery mode, and intensity, most interventions aimed to address similar problems, including reducing caregiver burden, enhancing family function, improving clinical care and the home environment, improving condition-specific symptoms, and increasing family knowledge about health care resources.

The studies showed a mixed pattern of intervention effects on caregiver or care recipient outcomes. Adverse effects and household economic status outcomes were not reported. Only 3 studies examined family function, and 1 study examined mental health service use. Only couples-based therapy for PTSD symptoms was given a moderate strength of evidence rating. All others were rated low or very low. Strength of evidence was rated on the basis of study design, risk of bias, inconsistency, indirectness, and imprecision. A more detailed discussion is in the Strength of Evidence section of the full report.

Clinical and Policy Implications

Other VA ESP reports have examined the impact of interventions for caregivers of patients with mental illness, cognitive impairment, and cancer. Our findings are similar to those of prior high-quality systematic reviews that examined the impact of interventions for caregivers of patients with mental illness, cognitive impairment, and cancer on both caregiver outcomes and patient outcomes. Collectively, these reports suggest some promise for effects of multicomponent interventions on caregiver psychological, burden, and quality-of-life outcomes.

The implications of our review for VA are unclear; however, there are likely some lessons learned about intervention delivery and outcome measurement that could inform research and implementation efforts in VA, particularly the content and delivery of these specific components. For example, it may be more effective to focus on 1 or 2 outcome goals and then refine content, delivery strategy, target participant (*ie*, care recipient vs caregiver), and intervention intensity to specifically address those outcomes. In addition, important patient- and caregiver-centered outcomes may be difficult to quantify, and several studies questioned whether short-term follow-up periods, such as a year or less, are sufficient to identify changes in psychological symptoms and other outcomes. More theoretical models are needed to inform discrete study goals, intervention designs, testable hypotheses, and explanations for the observed findings. Such theoretical models would provide a benchmark for more in-depth analysis about what did and did not work and would thus move the field forward.

Applicability

Of the 13 studies, 4 (31%) were conducted specifically in Veterans, and thus are highly applicable to the Veteran population. All but 2 studies were conducted in North America, and the rest were conducted in other economically developed countries. Most studies were conducted since 2005. However, many of the studies enrolled patients with TBI sustained in noncombat situations. Veterans with TBI often have coexisting PTSD, and thus findings in civilian patients may not generalize well to Veterans.

Limitations/Research Gaps/Future Research

We found no evidence for effects in patients with polytrauma and sparse evidence in patients with PTSD. There was also no evidence on which caregivers and patients are most likely to benefit or on the effect of financial support. For other types of interventions, there is uncertainty about the relationship between outcomes and intervention dose, mode of delivery, and components. Outcome measures varied greatly across studies. There was high heterogeneity in most studies.

Conclusions

There is a small but growing literature about family caregiver interventions for patients with trauma-based conditions, including TBI and PTSD. Overall, we identified a diverse set of interventions; the majority included a family illness education component, and many utilized skills-based curricula to promote environment modifications, improvements in condition-specific skills, caregiver self-care, and coping skills. Evidence about the impact of these interventions on care recipient and caregiver outcomes is inconclusive given the small literature, few patients, and the heterogeneity of intervention format, delivery, intensity, family involvement, and outcomes. Yet, for several outcomes, such as caregiver burden and psychological symptoms, caregiver interventions may be a promising approach. The positive impact of caregiver interventions on caregiver distress aligns with some prior reviews across a variety of patient conditions; however, there remain considerable gaps. No studies have been published that examine caregiver interventions for individuals with polytrauma. No studies that were eligible examined financial assistance interventions. Few studies examined patient- or caregiver-reported outcomes, and study quality was low.