Hidden Heroes

America’s Military Caregivers

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Who is caring for disabled veterans?

What resources are available to caregivers?

Where are there gaps?
Methods and approach

Phase 1
- Literature review
- Focus groups/conversations with military caregivers

Phase 2
- National survey of caregivers
- Comprehensive environmental scan
National survey of caregivers

Sample
1,129 military caregivers
1,828 civilian caregivers
1,163 non-caregivers
9% of U.S. adults are caregivers
5.5 million military caregivers
1.1 million post-9/11 military caregivers
Describing Caregivers
Post-9/11 caregivers
Younger
Post-9/11 caregivers

Younger

More likely to be a spouse, friend, or parent
Post-9/11 caregivers

Younger
More likely to be a spouse, friend, or parent
Less likely to have a support network
Post-9/11 caregivers

Younger

More likely to be a spouse, friend, or parent

Less likely to have a support network

More likely to be employed
Describing Care Recipients
Post-9/11 care recipients

More likely to have a behavioral health problem
Behavioral health: 64% Post-9/11, 36% Pre-9/11, 33% Civilian

Traumatic brain injury: 20% Post-9/11, 10% Pre-9/11, 10% Civilian

Chronic (e.g., cancer): 35% Post-9/11, 77% Pre-9/11, 63% Civilian

Neurological: 6% Post-9/11, 31% Pre-9/11, 29% Civilian
Post-9/11 care recipients

More likely to have a behavioral health problem

More likely to have a disability rating
% of care recipients with a disability rating

Post-9/11 care recipients: 58%
Pre-9/11 care recipients: 30%
Caregiving Duties
Help with at least 1 activity of daily living
Help with at least 1 instrumental activity of daily living
Help care recipient cope with stressful situations
Annual public value of caregiving

Post-9/11

Pre-9/11

Civilian

$3 billion

$10.6 billion

$41 billion
Burden of Caregiving
% of caregivers meeting criteria for probable depression

- Post-9/11: 38%
- Pre-9/11: 19%
- Civilian: 20%
- Non-caregiver: 10%

Consistent with general population
Confirmed predictors of major depression among post-9/11 caregivers

Demographics (race/ethnicity, sex, age, marital status)

Education level

Type of disability

Household income/characteristics

Relationship to care recipient

Time spent caregiving

Helping care recipient cope with stressful situations
No health insurance:
- Post-9/11: 32%
- Pre-9/11: 18%
- Civilian: 23%
- Non-caregiver: 19%

No regular source of health care:
- Post-9/11: 28%
- Pre-9/11: 12%
- Civilian: 14%
- Non-caregiver: 14%
% of caregivers reporting work schedule adjustments

- Post-9/11: 47%
- Pre-9/11: 23%
- Civilian: 27%
$5.9 billion per year in lost productivity
Resources for Caregivers
Methods and approach

**Phase 1**
- Literature review
- Focus groups/conversations with military caregivers

**Phase 2**
- National survey of caregivers
- Comprehensive environmental scan
Identifying support programs

- Web searches
- Meetings and events
- Consultations with program staff and experts
- National Resource Directory
- Snowball sampling
Support programs for caregivers

Social support: 53
Helping hand: 52
Education/training: 37
Wellness activities: 21
Patient advocacy: 21
Mental health care: 13
Respite care: 9
Religious support: 4
Health care: 4
Financial stipend: 3
Helping caregivers provide better care

- Social support: 53
- Helping hand: 52
- Education/training: 37
- Social support: 53
- Helping hand: 52
- Education/training: 37
- Patient advocacy: 21
- Wellness activities: 21
- Mental health care: 13
- Respite care: 9
- Religious support: 4
- Health care: 4
- Financial stipend: 3
Promoting caregiver well-being

- Social support: 53
- Helping hand: 52
- Financial stipend: 3
- Religious support: 4
- Health care: 4
- Respite care: 9
- Mental health care: 13
- Education/training: 37
- Wellness activities: 21
- Patient advocacy: 21
Helping caregivers’ families

- Social support: 53
- Helping hand: 52
- Education/training: 37
- Wellness activities: 21
- Patient advocacy: 21
- Mental health care: 13
- Respite care: 9
- Religious support: 4
- Health care: 4
- Financial stipend: 3
Compensating for income loss
Gaps in service

Programs address veterans’ needs, not caregivers’

Eligibility targets older beneficiaries (60+), especially at the state level

Younger/non-family caregivers often ineligible
The Future of Caregiving
Threats to the future of caregiving: aging parents and young marriages

25% of post-9/11 caregivers are parents

% over 75 years old

2013 2018 2023 2028

Post-9/11 caregivers

Perceived quality of caregiver-recipient couples’ relationships

5.0

3.4
Threats to program sustainability

Program maturity

Vulnerability to waning interest and support

Novel approaches that lack evidence of effectiveness
A path to better support
Empower caregivers

Recommendations

Provide training and continuing education

Improve health care coverage and structured support for better health

Raise awareness to match caregivers with services and boost public support
Create caregiver-friendly environments

Recommendations

Make workplaces more caregiver-friendly by training employers and offering supportive services

Make health care settings more caregiver-friendly by training and educating providers
Fill gaps in programs and services

Recommendations

Align resources and eligibility for program participation

Expand respite care
Plan for the future

Recommendations

Provide for long-term needs

Enable sustainable programs

Ensure access to quality services

Invest in research
VA Caregiver Support Program Update

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September 18, 2014
Mission Statement: To promote the health and well-being of family Caregivers who care for our nation’s Veterans, through education, resources, support, and services.

- Allow Veterans to remain at home in the community
- Address specific needs of Family Caregivers with a menu of programs and services
- Promote Veteran & Caregiver health and well-being
- Provide one location to obtain needed information
- Provide training & information on common conditions
- Reduce isolation with professional & peer support
- Provide options to give Caregivers respite
- Sensitize health care providers to the Caregivers’ role
Menu of VA Services

**In-Home Care**
- Skilled Nursing
- Home Health Aide
- Home Based Primary Care
- Veteran Directed Home & Community Based Care

**Respite Care**

**Services to Address Mobility**
- Equipment
- Home Modification
- Automobile Modification

**Education and Training**

**Financial Support**
- Aid and Attendance
- Caregiver Stipend (Post 9-11)

**Information and Referral**
- Caregiver Web site: [www.caregiver.va.gov](http://www.caregiver.va.gov)
- Caregiver Support Line: 1-855-260-3274

**Caregiver Support**
- Caregiver Support Coordinators
- Peer Mentoring Program
- Building Better Caregivers™
- Spouse Telephone Support
- REACH VA
- Support Groups
Caregiver Outreach

Caregiver Support Line

• More than 145,000 calls received
• Averaging ~ 200 calls per day

Caregiver Web site

• List serve members = 39,000+
• Average visits per day = 866
• Pages viewed per visits = 3

www.caregiver.va.gov
Caregiver Education, Training, and Support
Expanding Evidence-Based Interventions & Best Practices

**REACH VA**
- Designed to provide education support, and teach problem-solving for Caregivers of Veterans with Alzheimer’s Disease/dementia
- Currently being expanded to MS, Mental Health, and SCI/D

**Spouse /Caregiver Telephone Support**
- Groups of Post 9/11 spouses meet with a VA clinician to learn problem solving skills, resiliency training, and to receive support
- Currently being expanding to broader audience

**Building Better Caregivers™**
- An interactive, web based workshop developed by Stanford University and provided in partnership with the National Council on Aging (NCoA)

**Peer Support Mentoring Program**
- New Caregivers are matched to more experienced Caregivers
Program of Comprehensive Assistance for Family Caregivers – Program Overview

• Clinical Program, providing the following additional services directly to Family Caregivers of eligible Veterans injured in the line of duty on or after September 11, 2001:
  – Stipend
  – Enrollment in CHAMPVA
  – Mental Health
  – Beneficiary Travel
  – Education and Training
  – Additional respite

• Program participation **must**:
  – Be in the clinical best interest of the Veteran
  – Support the Veteran’s progress in treatment
Veteran or Servicemember undergoing medical discharge incurred or aggravated a serious injury in the line of duty on or after September 11, 2001 (includes Traumatic Brain Injury, psychological trauma or other mental disorders).

**and**

Veteran or Servicemember requires on-going assistance from a Caregiver for a minimum of 6 months to:

- Assist with the management of personal care functions required in everyday living;
- Significantly enhance the Veteran’s or Servicemember’s ability to live at home safely;
- Support the Veteran or Servicemember’s potential progress in rehab.

**Note:** there are additional criteria beyond what is listed here.
Program of Comprehensive Assistance for Family Caregivers – Current Data*

- Applications filed: 35,258
- Participating Caregivers/Veterans: 17,367
  - Tier 3 – 6,573 (stipend national average $2,330 per month)
  - Tier 2 – 6,616 (stipend national average $1,510 per month)
  - Tier 1 – 4,178 (stipend national average $630 per month)
- New Healthcare Coverage enrollees: 4,577
- Caregiver Demographics:
  - Gender: 91% women
  - Relationship: spouses (77%), parents (12%)
  - Age: 26-40 yrs old (53%), 41-64 years old (35%)

*Data current as of September 8, 2014
Program of Comprehensive Assistance for Family Caregivers
Caregiver Education and Training

Standardized Core Curriculum
- Developed in collaboration with Easter Seals
- In-person, workbook/DVD, or web-based
- Includes modules on:
  Caregiver Self-Care
  Home Safety
  Basic Caregiver Skills (vital signs, etc)
  Providing Personal Care
  Managing Challenging Behaviors
  Resources (legal, financial, VA, community, advocacy)

Training Data Update:
- More than 21,900 Family Caregivers have completed training to date
In FY 2013, healthcare utilization of a cohort of nearly 9,000 Veterans participating in the Program of Comprehensive Assistance for Family Caregivers was reviewed during the six months before participating and during the first six months of participation.

- Preliminary findings demonstrate:
  - An average decrease of 30% in inpatient admissions
  - A 2.5-day average reduction in the number of days spent in the hospital if the eligible Veteran was hospitalized
  - A 5% average decrease in the number of outpatient visits per month for eligible Veterans
Launch of CSP’s Caregiver Partnered Evaluation Center

Program Launch: June 1, 2014

- **Aim 1:** Assess the impact of the Comprehensive Program on the health and well-being of Veterans by examining health care encounters expected to be sensitive to Caregiver support (potentially avoidable utilization).

- **Aim 2:** Assess the impacts of the Comprehensive Program on the health and well-being of Primary Family Caregivers.

- **Aim 3:** Understand how Caregivers use and value components of the Comprehensive Program and the General Program.

- **Aim 4:** Generate a detailed profile of the costs and services provided under the Comprehensive Program and the General Program.
Questions?

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Atlas Research is a partner on the Easter Seals NVCTP. Atlas Research is an award-winning, SDVOSB consulting firm providing strategic advisory, education and training, and applied research to federal health and social service agencies. Atlas Research is the leading contractor in the Veterans’ Homelessness Space.
Caregiver Self Care Education and Training

• In 2013, the VA Caregiver Program moved forward with adding Self Care courses for General Caregivers
• Caregiver Self Care Courses are designed for Caregivers of Veterans of all era’s enrolled in the VHA
• Courses are offered as Face to Face classroom sessions throughout the Country and Territories in English and Spanish.
Caregiver Self Care  Education and Training

• The General Self Care Series includes four courses:
  – Stress Management
  – Communication and Problem Solving
  – Taking Care of Yourself
  – Utilizing Technology

Courses were deployed in October 2013 and to date we have trained 1223 Caregivers of WW II, Korea, Vietnam, first Gulf War, Operation Iraqi Freedom, Enduring Freedom, and New Dawn Veterans.
Caregiver Self Care Education and Training

• All courses are facilitated by 2 trainers that are licensed health care professionals
• Approximately 20 trainers are located across the country and originate from Easter Seals affiliates or partner organizations
• Cultural competence is an essential part of Train the Trainer sessions while interacting with vastly different cultures (Puerto Rico, Samoa)
USO Warrior and Family Care Caregiver Education Series

• Joint effort between USO, Easter Seals and Atlas Research to develop Caregiver materials directed toward Caregivers of Recovering Service Members

• USO Caregiver Education Series includes four courses:
  – Strategies for Taking Care of Yourself
  – Strategies for Managing Stress
  – Strategies for Addressing Challenging Behavior
  – Strategies for Accessing Caregiver Resources
Elizabeth Dole Foundation’s National Coalition for Military Caregivers

• Collaborated with the Dole Foundation for Military Caregivers to present a series of six webinars available to the general public

• To date the following webinars have been produced:
  – From Daunting to Doable: The Power of Caregiver Resilience.”
  – Military Caregivers in the Workplace
  – Military Strong: Receiving with Grace
Elizabeth Dole Foundation’s National Coalition for Military Caregivers

• Next webinar scheduled for November 13
• Dealing with the Caregiver “Blues”, when it becomes Depression.
• Webinars are being supporting by an incredible group of organizations. They include:
  – Atlas Research
  – Caregiver Action Network
  – Family Caregiver Alliance
  – National Alliance for Caregiving
  – Rosalynn Carter Institute for Caregiving
  – USO
Final thoughts

- By and large this is a very different, younger Caregiver cohort
- Only 1% of our Country’s population have been deployed to war zones over the past decade
- Many of the Service members have been deployed 3-4 times
- 99% of the Country’s population does not have direct exposure to the perils of war and sequelae experienced by Service Members and their families
Questions

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