SUPPORTING THE CAREGIVERS OF VETERANS WITH SPINAL CORD INJURY/DISEASE

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Objectives

1. To discuss the benefits of recognizing and assessing levels of caregiver stress/burden. This will include discussion of valid and reliable assessment tools.

2. To present current data concerning the levels of caregiver stress/burden in primary caregivers of individuals with SCI and its potential impact on the health of patients.

3. To provide data from FY 12 and FY 13 regarding the interventions offered to caregivers and their roles in decreasing caregiver burden, allowing for better care of veterans/individuals with SCI.
More than 65 million people, 29% of the U.S. population, provide care for a chronically ill, disabled or aged family member or friend during any given year and spend an average of 20 hours per week providing care for their loved one.

(National Alliance for Caregiving in collaboration with AARP; November 2009)
46% of family caregivers in the U.S. perform medical and nursing tasks.

Three out of four provide medication management – including administering IVs and injections – for a family member with multiple chronic physical and cognitive conditions.

More than a third of these caregivers providing medical and nursing tasks reported doing wound care.

Other tasks include operating specialized medical equipment and monitors. (United Hospital Fund and the AARP Public Policy Institute-Sept. 2012)
The value of the services family caregivers provide for "free," when caring for older adults, is estimated to be $375 billion a year. That is almost twice as much as is actually spent on homecare and nursing home services combined ($158 billion).

(National Alliance for Caregiving and Evercare; March 2009)
Caregiver/Patient Relationship

“Identifying caregivers’ concerns and needs can lead to more effective strategies for optimal functioning of patients.” (Zarit, 2007)

“It makes sense clinically to assess caregivers... This leads to best clinical decisions for patients.” (Zarit, 2007)
Health Effects of Caregiving

2012 - Harvard School of Public Health

- 8 year study looking at association between spousal caregivers (age 50+) and the incidence of Cardiovascular Disease (CVD)
- Long term caregivers risk for CVD doubled over their non-caregiving peers.

2012 - Instituto Andaluz de Neurociencia y Conducta, Málaga, Spain

- Study focused on coping strategies and psychological distress in caregivers of Alzheimer's patients.
- Increase in depression and anxiety
Signs of Stress/Burden

- Stressed caregiver presents with some of the following feelings/emotions.
- Burdened caregiver presents with several of the following feelings/emotions:
  - Anger, Anxiety
  - Distress, Exhaustion
  - Guilt, Helplessness
  - Isolation, Vulnerability.
AMBIGUOUS LOSS: situation or problem with no answer or resolution that can immobilize grief and coping processes

- Stressful type of loss due to ambiguity
- Has the potential to disturb systemic processes
- Physical absence with psychological presence
  - Missing persons, in kidnapping, war or terrorism
- Psychological absence with physical
  - Dementia, depression & other chronic mental illness, physical disability and chronic physical illness
Types of Ambiguity

Family membership ambiguity
- Who is in the family now?
- Has it changed?

Roles and rules ambiguity
- How have family rules changed as a result of illness/injury?
- Adapting to caregiver role

Rituals ambiguity
- Impact of illness/injury on family celebrations, events and rituals.
Spousal/Partner Caregiving

- Illness is one member of the couple changes the caregiving relationship
- Despite ‘caregiver burden’, caregivers experience satisfaction, self worth & higher self esteem
- Caregivers may begin to grieve impending loss
Impact Of Illness Onset

Has the onset of the illness been acute?
- Traumatic Spinal Cord Injury

Is the illness chronic and/or relapsing?
- Non-Traumatic Spinal Cord Disease

Impacts Caregiving Relationship
Work With Caregiver

- Caregiver’s limitations and emotional needs
- Desire to protect care receiver from burden of worry
- Need for reciprocal systemic arrangement for the couple
Caregiver Assessment

- Identifying caregiver needs and concerns can result in more effective strategies for optimal patient functioning.
- Good assessment includes caregiving demands and stressors, secondary stressors, personal resources, social resources and risk factors.
- Should result in a care plan developed with the patient and the caregiver (Zarit, 2007)
Caregiver Assessment Tools

- Caregiver Strain Index
- Caregiver Burden Scale
- Caregiver Burden Interview
- Zarit Burden Interview
Caregiver Strain Index

- Measures caregiver strain using yes/no response scales.
- 12 items (2-point scale)
Caregiver Burden Scale

Measures caregiver burden at the end of life.

18 items (4-point scale)

Caregiver Burden Interview

To measure caregiver burden as it relates to time, developmental comparison with peers, physical health, social relationships, and emotional health.

5 items for each: a) time-dependence burden; b) developmental burden; c) physical burden; d) social burden (5-point scale)

4 items for emotional burden (5-point scale)

Zarit Burden Interview

- Measures caregiver appraisal of the impact of caregiving.
- 22 items (5-point scale) – Long form
- 4 items – Short form
Caregivers accompanying veterans with SCI/D to comprehensive annual exam competed Zarit Burden Interview (SF)

Those with scores of 8+ on scale of 0-16 were asked to Complete Zarit Burden Interview (LF)

Caregivers seen on SCI Homecare visits were given the same assessments
Do you feel your relative asks for more help than he/she needs?
Do you feel that because of the time you spend with your relative, you don’t have enough time for yourself?
Do you feel stressed between caring for your relative and trying to meet other responsibilities to your family or work?
Do you feel angry when you are around your relative?
Interview Responses

Responses:
- Never (0)
- Rarely (1)
- Sometimes (2)
- Quite Frequently (3)
- Nearly Always (4)
0 – 5: Little or No Burden

6-10: Mild to Moderate Burden

11-15: Moderate to Severe Burden

16-20: Severe burden
Scoring the Zarit (LF)

- **0 – 21**: Little or No Burden
- **21-40**: Mild to Moderate Burden
- **41-60**: Moderate to Severe Burden
- **61-88**: Severe burden
At VA BHS, several caregivers during clinic appointments or home visits spoke of stresses involved in caring for their loved ones with SCI. FY 12 at VABHS assessments showed:

- 31% of at home caregivers in SCI/D surveyed VABHS reported high moderate to severe burden.
- 75% of at home caregivers in SCI/D reported that their own health had suffered while caring for the veteran.
FY 13 Caregiver Assessments

- Question added to Zarit SF
  - Do you feel your health has suffered because of your involvement with your relative?
- Expanded assessment to 4 VISN 1 Medical Center SCI Primary Care Clinics
  - VA Connecticut HS - Jane Coffee, LICSW
  - VA Maine HS - Mark Kmen, LICSW
  - White River Junction VA MS - Michelle Turcotte-Smail, LICSW
Caregiver Resources

- List of Caregiver Resource for all 4 Medical Centers
  Included names and contact information for each resource at each site

- Resources include Inpatient Respite, In Home Respite, 4 Telephone Caregiver Support Groups (1 dedicated to caregivers of Veterans with ALS, online and local resources)
Caregiver Resources

- Resources discussed with individual caregivers as needed
  - Caregivers took home copy of resources list
- Discussions with caregivers as needed regarding
  - Importance of Self Care
  - Importance of Addressing Health Issues
  - PCP appointment to address symptoms of anxiety and depression
Reported Caregiver Burden

- Little or No Burden: 46%
- Mild to Moderate: 45%
- Moderate to Severe: 9%
- Severe Burden: 0%

N=69
Reported Health Impact

- Never: 37%
- Rarely: 35%
- Sometimes: 25%
- Quite Frequently: 3%
- Nearly Always: 0%

N=57
Looking Forward

- Reach out to caregivers who do not accompany veterans to Annual Evaluation
- Provide caregiver education using inter-facility CVT and/or VANTS
- Provide caregivers with stress reduction protocol
References

- *Caregiving in the United States*; National Alliance for Caregiving in collaboration with AARP; November 2009.
References

- *Home Alone: Family Caregivers Providing Complex Chronic Care-* United Hospital Fund and the AARP Public Policy Institute; September 2012.
References


Thank You

Questions? Comments?