Burden Among Caregivers of Adults with Spinal Cord Injury
Shriners Hospitals for Children, Chicago
Marquette University
Susan Ryerson Espino, PhD
Lawrence C. Vogel, MD
Erin H. Kelly, PhD (American Academy of Pediatrics)
Gerald Harris, PhD
Kathy Zebracki, PhD
Titilope Akinlose, MPH

Hines VA Hospital
Azadeh Ghaffari, PhD
Michael Richardson, MD

Rehabilitation Institute of Chicago
David Chen, MD
Debbie Pucci, PT

Schwab Rehabilitation Hospital
Ray Lee, MD
Kris Balfanz-Vertiz, MSW/LSW
Caroline Taromino
Disclosure Information
PVA Summit 2016
August 30 – September 1, 2016

Speaker Name: Lawrence C. Vogel, MD

I have the no financial relationships to disclose

Department of Defense Grant SC130279
Learning Objectives

• Enhance our understanding of the relationships between QOL of caregivers, caregiver burden, and QOL of veterans and other adults living with SCI

• Explore unmet needs of caregivers

• Develop initiatives to improve caregiver physical and emotional health, including self-care and connections with others
Presentation Outline

• Project Overview
  • Background
  • Methodology

• Initial Findings and Interpretation of Data
  • Qualitative
  • Quantitative

• Future Direction/Implications
  • Intervention development
Importance of Caregivers

• For many individuals with SCI, caregivers are critical in terms of their health and well-being
  • Assist in everyday activities
    • Bladder and bowel
    • Food preparation and feeding
    • Bathing and dressing
    • Housework
  • Prevention/Rx of complications and health maintenance
    • Pressure ulcers
    • UTIs
    • Autonomic dysfunction
  • The care they provide helps to control healthcare costs
Physical & Emotional Toll of Caregiving

• Mental health issues
• Physical health issues
• Reduced sleep
• Reduced social support and self-efficacy
• Loss of sense of self
• Changing priority of personal needs
• Quality of life
Factors found to be related to greater caregiver burden

- Female caregivers
- Less educated
- Living with their family member with a SCI
- Employment outside of the home
- Caring for individuals with recent injuries
- Caring for individuals with greater needs
Factors found to be related to less caregiver burden

- Assistive technology
- Home and community accessibility
- Social support
- Positive perception of role and contribution
- Social integration and fewer negative social interactions
- Participation in meaningful activities outside of the home
- Adaptive coping
- Relationship dynamics: maintaining open communication with person with SCI
Project Overview
Project Objective

• Investigate the process of adjustment for caregivers of adults with SCI
• Investigate the dynamic interplay between characteristics of caregivers and those they care for
• Basis for interventions to boost resilience and health
• 4 project aims
Aim 1

Examine how being a caregiver impacts caregivers’
  • Mental and physical health
  • social integration
  • intimacy
  • participation in meaningful activities such as career development

How does being a caregiver impact the caregiver’s quality of life (QOL)?
Aim 2

• Identify differences in experiences between caregivers of veterans and caregivers of civilians with SCI, across a variety of SES groups
• Examine how caregiver adjustment is facilitated or inhibited by
  • personal factors
  • family and community support and resources

How does the experience of caregiving vary by certain caregiver characteristics?
Aim 3

• Examine how the health of individuals with SCI relates to the health of their caregivers
• How does this relationship change over time

How does the health of individuals with SCI relate to the health of their caregivers?
Aim 4

• Propose core intervention components to improve caregiver adjustment
  • specific recommendations for interventions for caregivers of veterans and civilians from diverse SES backgrounds.

How can we help improve caregiver QOL?
Overview of Design

Multi-site study with participants being recruited from four area hospitals across Chicagoland.

Participating Sites:
1. Shriners Hospitals for Children – Chicago
2. Schwab Rehabilitation Hospital
3. Rehabilitation Institute of Chicago
4. Edward Hines, Jr. VA Hospital

48 individuals with spinal cord injury (SCI) and their primary caregivers will be recruited. Approximately 16 individuals with SCI will be veterans and 32 will be civilians.
Eligibility Criteria

For persons with SCI:

- SCI sustained at 17 years of age or older
- Injury duration of at least one year
- Participant is between the ages of 18-65
- Participant has someone in his/her life who cares for them, physically or emotionally – a Caregiver
- Participant and caregiver speak English
- Participant and caregiver can cognitively answer questionnaires
Eligibility Criteria

Caregivers:

• Caregivers will have
  • provided physical or emotional support to the person with SCI for at least 6 months
  • will have regular contact with the person with SCI (face-to-face contact at least once per week)
  • will live with or near the individual with SCI
Eligibility Criteria

Caregivers:

• Caregivers
  • Spouses, family members, or close family friends
  • Will be clearly identified as the primary caregiver by the individual with SCI and their caregiver

• Excluded
  • Formal caregivers who solely have a financial relationship with the person with SCI (i.e., paid personal care attendants who are not family members or close family friends)
**Schematic of Study Design**

**Recruitment Sites**
- Pediatric Rehab Hospital
- Inner City Rehab Hospital
- Downtown Rehab Hospital
- VA

**Screening/Enrollment**
- Screen referrals. Obtain informed consent

**Study Visit 1**
- Semi structured interviews are conducted separately with caregivers and individuals with SCI. They then complete a packet of project questionnaires and quantitative surveys

**Study Visit 2**
- Follow up interviews 15 months following first interviews

**Analyses**
- Qualitative and Quantitative Analyses

**Ensure credibility of data**
- Advisory Board oversight and Focus Groups with participants to discuss findings and confirm interpretations
Qualitative Interview Protocols

DOMAINS - Interviews focus on:

• Caregiving tasks and responsibilities
• The person with SCI’s injury (injury context)
• Relationship dynamic between person with SCI and caregiver
• Challenges and rewards of caregiving
• Met and unmet needs
Qualitative Interview Protocols

Specific to the Caregiver Impact of Caregiving on:

• Emotional Health
• Physical Health
• Social Integration
• Intimacy
• Participation in meaningful activities
Quantitative Surveys: Person with SCI

- Demographics questionnaire
- International SCI Data Sets
  - Core data sets
  - Basic data sets
    - pain
    - bowel function
    - lower urinary tract function
    - quality of life
    - activity and participation
Quantitative Surveys: Person with SCI

- Pressure ulcer questions (long-term outcomes of adults with pediatric-onset SCI)
- Hospital Anxiety and Depression Scale (HADS)
- PTSD Checklist-Civilian Version (PCL-C)
- The Craig Handicap Assessment and Reporting Technique (CHART-SF)
Quantitative Surveys: Caregivers

- Demographics questionnaire
- Social support questions
- Leisure Time Satisfaction
- International SCI QOL Basic Data Set
- The Pennebaker Inventory of Limbic Languidness (PILL)
- Hospital Anxiety and Depression Scale (HADS)
- Zarit Burden Inventory (ZBI)
Recruitment Challenges

• IRB challenges with multi-site studies

• Restrictive eligibility criteria
  • Recently expanded age of person with SCI from 25-44 to 18-65
  • Inclusive of non-traumatic SCI cases

• Use of the word “caregiver”
  • Eligible participants not considering themselves a caregiver

• Centralized enrollment and data collection lead by non-provider (for all but former pediatric rehab participants)
Initial Findings

Quantitative Data
Person with SCI (n=22)

- Age at injury, mean = 21 years (SD = 5.0)
  - Range = 17-37

- Current age, mean = 37.1 years (SD = 6.2)
  - Range = 26-53 years

- 68% Caucasian

- 59% Motor vehicular crashes

- 77% tetraplegia

- 5/22 are veterans
### Caregivers:

- **Mean age** = 50 years (SD = 15.8)
  - Range = 22-77 years
- 59% Caucasian
- 77% female
- 82% high school educated or higher
- 50% parent
- 36% spouse or significant other
- 9% sibling
- 5% other relative
- 32% employed (43% full-time)
# The Pennebaker Inventory of Limbic Languidness (PILL)

<table>
<thead>
<tr>
<th>Domain</th>
<th>M(SD), range</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-21</td>
<td>below normal range</td>
</tr>
<tr>
<td>22-66</td>
<td>well within normal</td>
</tr>
<tr>
<td>67-84</td>
<td>slightly above average, within normal</td>
</tr>
<tr>
<td>&gt;84</td>
<td>top 25 percent</td>
</tr>
<tr>
<td></td>
<td>40.5 (25.1), 2-112</td>
</tr>
</tbody>
</table>
**Leisure Time Satisfaction**

<table>
<thead>
<tr>
<th>Domain</th>
<th>M(SD), range</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 not at all</td>
<td>7.7 (3.0), 2-12</td>
</tr>
<tr>
<td>6 a little</td>
<td></td>
</tr>
<tr>
<td>12 all the time</td>
<td></td>
</tr>
</tbody>
</table>
## Social support

<table>
<thead>
<tr>
<th>Domain</th>
<th>M(SD), range</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-not at all</td>
<td></td>
</tr>
<tr>
<td>1-a little</td>
<td></td>
</tr>
<tr>
<td>2-moderately</td>
<td></td>
</tr>
<tr>
<td>3- very satisfied</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with instrumental support</td>
<td>2.1 (.7), 0-3</td>
</tr>
<tr>
<td>Satisfaction with emotional support</td>
<td>2.1 (1.0), 0-3</td>
</tr>
<tr>
<td>Satisfaction with informational support</td>
<td>2.0 (.9), 0-3</td>
</tr>
</tbody>
</table>
## Hospital Anxiety and Depression Scale

<table>
<thead>
<tr>
<th>Domain</th>
<th>M(SD), range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HADS Depression</strong></td>
<td></td>
</tr>
<tr>
<td>normal 0–7</td>
<td>4.7 (4.4), 0-16</td>
</tr>
<tr>
<td>mild 8–10</td>
<td></td>
</tr>
<tr>
<td>moderate 11–14</td>
<td></td>
</tr>
<tr>
<td>severe 15–21</td>
<td></td>
</tr>
<tr>
<td><strong>HADS Anxiety</strong></td>
<td></td>
</tr>
<tr>
<td>normal 0–7</td>
<td>6.4 (4.4), 1-18</td>
</tr>
<tr>
<td>mild 8–10</td>
<td></td>
</tr>
<tr>
<td>moderate 11–14</td>
<td></td>
</tr>
<tr>
<td>severe 15–21</td>
<td></td>
</tr>
</tbody>
</table>
## Summary of Quantitative Indicators

<table>
<thead>
<tr>
<th>Domain</th>
<th>M(SD), range</th>
<th>“Flags”</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Leisure Time</strong> (0-not at all, 6-a little, to 12 – all the time)</td>
<td>7.68 (3.00), 2-12</td>
<td>32% (7/22)</td>
</tr>
<tr>
<td><strong>PILL</strong> (0-21, below normal range; 22-66, well within normal; 67-84, slightly above average, within normal; 85 or above, top 25%)</td>
<td>40.45 (25.12), 2-112</td>
<td>5% (1/22)</td>
</tr>
<tr>
<td><strong>Satisfaction</strong> (0-not at all, 1-a little, 2-moderately to 3- very satisfied) with Instrumental Support</td>
<td>2.14 (.71), 0-3</td>
<td>9% (2/22)</td>
</tr>
<tr>
<td>with Emotional Support</td>
<td>2.05 (1.00), 0-3</td>
<td>27% (6/22)</td>
</tr>
<tr>
<td>with Informational Support</td>
<td>2.00 (.87), 0-3</td>
<td>27% (6/22)</td>
</tr>
<tr>
<td><strong>HADS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression (normal 0–7, mild 8–10, moderate 11–14, severe 15–21)</td>
<td>4.73 (4.42), 0-16</td>
<td>14% (3/22)</td>
</tr>
<tr>
<td>Anxiety (normal 0–7, mild 8–10, moderate 11–14, severe 15–21)</td>
<td>6.41 (4.39), 1-18</td>
<td>18% (4/22)</td>
</tr>
<tr>
<td>Any flag</td>
<td></td>
<td>55% (12/22)</td>
</tr>
</tbody>
</table>
## Caregiver QOL and Burden

<table>
<thead>
<tr>
<th>Domain</th>
<th>M(SD), range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall QOL</td>
<td>7.6 (2.1), 1-10</td>
</tr>
<tr>
<td>1 Completely dissatisfied</td>
<td></td>
</tr>
<tr>
<td>10 Completely satisfied</td>
<td></td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>1.0 (.8), 0-2.4</td>
</tr>
<tr>
<td>0 Never</td>
<td></td>
</tr>
<tr>
<td>1 Rarely</td>
<td></td>
</tr>
<tr>
<td>2 Sometimes</td>
<td></td>
</tr>
<tr>
<td>3 Quite frequently</td>
<td></td>
</tr>
<tr>
<td>4 Nearly always</td>
<td></td>
</tr>
</tbody>
</table>
Caregiver QOL and Burden

Caregiver QOL significantly related to burden
(-.78, p < .00)

Significant differences between those flagged for concerns and those not flagged (Mann Whitney U Test p < .01)

Those with flags report significantly
- Lower QOL
- More burden
How does the health of caregivers relate to the health of those living with SCI?
Outcomes of Adults with SCI

- Caregivers reporting higher burden ➔ higher anxiety among those with SCI
- Caregivers reporting lower QOL ➔ more pain among those with SCI
**Compensation & Support for Caregiving by VA Status**

Kinds of instrumental support: (1) compensation for caregiving, (2) supplemental care assistant
Initial Findings
Qualitative Data
Unmet Needs & Challenges
Qualitative

• Emotional functioning
• Physical well-being
• Self care
• Social integration
• Finances
• Future care plans
Emotional Functioning

“It’s very tiring, and it’s very lonely. Of course, it’s probably lonelier for me than it is for a lot of people, because I don't have my husband here either. If we could be working on this together, that would help take care of both of those things. I wake up tired because for five years I haven’t gotten to sleep the whole night through. And it’s lonely because my friends have kind of left me.”

Caregiver of Veteran, age 61
Respite Care

“I think (mom) could definitely use some downtime, you know, and time by herself. ...just something to kind of get away from us for a little while”

*Adult living with SCI*
Physical Well-Being

“I have back problems, which I take medicine for. I’ve got arthritis and stuff, but I take my medicine and I deal with what I can deal with. And sometimes we’re slow at it, and sometimes I'm faster at giving her a bath or getting her up.”

Caregiver of Civilian, age 56
Physical Well Being

“Well, the older I get, you know, the harder it is to move him... he's now no little-bitty boy either”

*Senior Caregiver of son who is over 6 feet tall*
Emotional & Physical Strain

“I'm wearing out ... I don't have much more to give to him emotionally or physically sometimes”

Caregiver
Self-Care

“Well, I do a lot of neglecting myself because of this situation, because I tend to put—and I would guess my sister does, too, tend to put her first, her well-being, what has to be done as far as she is concerned.

I think that comes first, prior to maybe what I might want to do.”

Caregiver of Civilian, age 55
“It absolutely impacts social life. Well, sure, because let’s say friends wanna go out dancing. That’s tricky. We can go out dancing. My husband and I can go out dancing, but you have to be—we have to think ahead like, “Okay, are there stairs to the dance floor? Is it too crowded? Is he gonna be able to get there?”

Caregiver of Veteran, age 42
Financial Challenges

• Insurance: Coverage issues for durable medical equipment
• Physical modifications to homes
• Future financial stability
“Yeah. Like I was saying, at times. That’s why I have to basically work, because his SSI would just pay our rent. Everything else depends on me. How is it going to get paid, because I have to have a job regardless of it. Because unless that doesn’t happen, then we’re not going to be able to live without it.”

*Caregiver of Civilian, age 22*
Future Care

• Concerns about health deteriorating for either member of the dyad
• Lack of communication about future or disagreements
• Anxiety
Future Care Plans

“In the next five years? Yeah. But I am in my early 40s, so I have—in the back of my mind, I have given thought to that eventually we’re gonna have to have some assistance. We’re gonna have to have an outside caregiver to some degree. Although now he’s very independent ... But eventually there’s gonna be a time where that’s not gonna be the case, just because of age.”

Caregiver of Veteran, age 42
Summary

• Caregivers with “red flags” report higher burden and less satisfaction with quality of life

• Varied factors contribute to caregiver burden and QOL
  • lack of leisure
  • mental health concerns
  • social support
  • physical health
Summary

• Significant relationships were identified between caregiver burden and QOL and pain and anxiety in adults with SCI

• Veteran dyads were more likely to report receiving compensation or additional caregiving support

• All caregivers qualitatively shared a variety of unmet needs
Implications

- Raising awareness on issues related to caregiver burden and quality of life
  - Future studies
  - Advocacy

- Launching initiatives to bolster caregiver QOL
  - Services offered under the Veteran Health Administration Directive 1176 (serves as a good model)
  - Caregiver compensation
  - Supplemental caregiving programs (training & respite)
  - Self-care strategies
  - Peer support program (support groups)
VHA Directive 1176

- The Veterans Health Administration (VHA) Directive 1176 defines procedures for the operation of the Spinal Cord Injury and Disorders (SCI/D) System of Care.

- Services that are Veteran centric, results oriented, and forward looking.
VHA Directive 1176

The mission of the VHA SCI/D System of Care is to support, promote, and maintain the health, independence, quality of life, and productivity of individuals with SCI/D throughout their lives. This is accomplished through:

• The efficient delivery of rehabilitation;
• Sustaining medical and surgical care;
• Patient and family education;
• Psychological, social, and vocational care;
• Research;
• Education; and
• Professional training in the continuum of care for persons with SCI/D.