Impact of TBI on Caregivers of Veterans with TBI: Burden and Interventions

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Poll Question #1

- What is your primary role in VA?
  - Student, trainee, or fellow
  - Clinician
  - Researcher
  - Administrator, manager or policy-maker
  - Other
PSYCHOSOCIAL IMPACTS
Brain Injury Caregivers

• Significant proportion of caregivers of individuals with BI experience:
  ✓ Psychological distress
  ✓ Psychological disorders
  ✓ Family disruption

BI Caregiver Adjustment

• Better adjustment associated with:
  ✓ Active coping strategies
  ✓ Perceived social support

• Avoidant coping strategies associated with maladjustment

[Sander et al, 1997; Curran et al, 2000; Ergh et al, 2002; Anson & Ponsford 2006]
Pre-injury Family Distress

• Sander et al (2003): 25-33% of families are already in significant distress when a family member sustains a TBI

• Family Assessment Device (FAD; Epstein et al, 2006) Global Index aids in triage
  ✓ A proportion of these may need intensive family therapy or “divorce” from identified patient
  ✓ Majority will benefit from coping skills/prevention approach
Ramchand et al. 2014

THE RAND STUDY
Sample

1,129 military caregivers
1,828 civilian caregivers
1,163 non-caregivers
RAND Study Findings

- 9% of U.S. adults are caregivers
- 5.5 million military and veteran caregivers
- 1.1 million are supporting a post-9/11 veteran
- 2.5 million civilian and military caregivers supporting a person with TBI
Describing TBI caregivers (military and civilian)

- Likely to be a related to care recipient
  - Spouse (29%)
  - Parent (24%)
  - Other family (24%)
- Mostly female (60%)
- Likely living with care recipient (55%)
- Rely on a caregiving network (67%)
- Serving in role for more than 3 years (63%)
- Just over a quarter support a veteran with TBI (28%)
The Rand Study

CAREGIVING DUTIES
ADLs Performed by TBI Caregivers

- Bathing: 50.2%
- Dressing: 48.1%
- Getting in/out of chair: 43.6%
- Dealing with incontinence: 36.7%
- Toileting: 35%
- Feeding: 34.9%
IADLs Performed by TBI Caregivers

- Transportation: 83.4%
- Managing Finances: 81.1%
- Grocery Shopping: 80.1%
- Housework: 79.9%
- Preparing Meals: 78.9%
- Administering Meds: 78.2%
Other Tasks Performed by TBI Caregivers

<table>
<thead>
<tr>
<th>Task</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help Remembering</td>
<td>79.3</td>
</tr>
<tr>
<td>Help Filling out Paperwork</td>
<td>87.4</td>
</tr>
<tr>
<td>Help Cope with Stressful Situations</td>
<td>75.1</td>
</tr>
</tbody>
</table>
The Rand Study

CAREGIVING

BURDEN
% of caregivers meeting criteria for probable depression

- TBI Caregivers: 39%
- All Civilian Caregivers: 20%
- Non-caregiver: 10%

Consistent with general population
Other Self Reported Adverse Impacts

Changes in personal plans: 61.6%
Feeling overwhelmed: 58.1%
Financial strain: 55%
Family adjustments: 54.7%
Confining: 53.4%
Emotional adjustments: 51%
Sleep disturbed: 51%
Inconvenient: 43.6%
ECONOMIC IMPACTS
Caregiving for Veterans with Polytrauma

- 62.3% of caregivers report depleted assets and/or accumulated debt
- 41% of working caregivers left labor force
- For Veterans needing intensive help, primary caregiver:
  - Faced 4.6 higher odds of leaving the labor force
  - Used $27,576 more assets and/or debt compared to caregivers of Veterans needing little or no assistance

[Van Houtven et al. 2012]
High costs emerged as a theme in 50 in-depth interviews with caregivers, some of whom cared for Veterans with TBI:

- Reduced caregiver employment
- Direct care costs
- Depletion of assets
- Costs related to Veteran behavior changes due to TBI reported by some caregivers:
  
  “He wanted to buy everything. He didn’t understand the concept of money and that we had to pay bills first.”
INTERVENTIONS FOR FAMILIES AND CAREGIVERS WITH BRAIN INJURY SURVIVORS
Early Family Intervention Studies

- Uncontrolled studies showed benefit of approach combining:
  - BI and community resource education
  - Cognitive-Behavioral Therapy (CBT)
    - coping skills
    - stress management
    - goal management

[Kreutzer & Taylor, 2004; Sander AM, 2008; Kreutzer et al, 2009]
FURTHER DEVELOPMENT & EVALUATION OF COPING SKILLS/SECONDARY PREVENTION APPROACH
Backhaus et al: Brain Injury Coping Skills Group (BICS)

• Includes both identified individuals with ABI and families
• Education, CBT coping skills training, and support
• 16 sessions
• Treatment manual available
• Initial RCT showed improvement in coping skills for BICS compared to waitlist control
• Follow-up, more tightly controlled RCT showed benefit for both professionally-directed and self-directed groups
• In both studies, participants were generally not in a pathological level of psychological distress
BICS Studies

Active ingredients may be:
✓ A supportive environment promoting high levels of engagement and low conflict
✓ Opportunities to frequently meet with the same individuals
✓ An organized structure supported by a facilitator
Brain Injury Family Intervention (BIFI)  
[Kreutzer et al. 2009, 2015]

- Similar components to BICS
- Included both individuals with TBI and their family members
- 5 two-hour sessions
- Conducted over a period of 10 years
- Included 108 BIFI group; 46 wait list controls
BIFI Study Results

- Primary dependent measure: Family Needs Questionnaire (FNQ)
- Pre- to post-treatment:
  - BIFI group significantly improved on 4 of the 6 FNQ subscales
  - Control group: no significant change on any FNQ subscale.
  - **However**, there was a significant difference between control and treatment group only on the Professional Support subscale
DEVELOPMENT OF MORE SPECIALIZED INTERVENTIONS
Couples CARE (Caring and Relating) [Backhaus et al. 2016, under review]

- Couples with one member with BI
- CBT
- Dialectical Behavior Therapy (DBT) methods
- Relationship counseling (Gottman Therapy)
- Improved satisfaction and quality of relationship
Veterans Multi-Family Group

[Perlick et al. 2013]

• 3 phases:
  ✔ Joining: clinicians met with individual families for two or three sessions to evaluate ongoing problems; & define treatment goals
  ✔ Veterans and families attended two three-hour educational workshops about TBI
  ✔ Veterans and their families attended problem-solving multifamily group meetings bimonthly for six months

• Uncontrolled trial documented:
  ✔ Decreased veteran anger expression, social support and occupational activity
  ✔ Caregivers reported decreased burden and increased empowerment
Veterans Multi-Family Group

- Qualitative analysis [Straits-Troster et al. 2013]
  - Exploring common struggles and reducing isolation
  - Building skills to cope with TBI and related problems
  - Restoring relationships through communication and understanding
  - Increasing understanding of the interconnection between TBI and posttraumatic stress disorder (PTSD)
  - Improving the multifamily group treatment experience and increasing engagement
Telehealth/web-based interventions [Rietdijk et al. 2012; McLaughlin et al. 2013]

• Preliminary evidence of efficacy for:
  ✓ Education & support
  ✓ Improved functioning of person with TBI
  ✓ Improved psychological wellbeing, support/advocacy skills and burden of family members
  ✓ Benefit maintained over the long-term

• Adults and children included
Limitations in Current Research

- Most studies are cross sectional
  - Assessing caregivers at specific time may eliminate past caregivers from study population
  - Unclear how economic strain impacts caregiver and Veteran over time
- Many still use convenience based samples
  - Unclear whether these samples may be biased
- Most rely upon self-report data for assessing impact; few employ pre-post objective assessments of health
Current Research Gaps

• Understanding the dynamic nature of caregiving
  ✓ Longitudinal studies of caregivers (with appropriate comparison groups)

• Efficacy and effectiveness of various programs and interventions on caregiver well-being and TBI outcomes

• Telehealth/web-based interventions

• Further evaluation of more specialized interventions for couples

• Estimating the impact of caregiving duties on children

• Examination of special needs/structure of military and veteran families
Potential Priorities for Future Research

- More definitive determination of who needs what (triage protocol)
  - Intensive intervention to address significant family distress and/or psychopathology vs. coping skills/prevention approach
- Further identification of active ingredients of coping skills approach and need for professional involvement
Other Research Considerations

- Interventional research plagued by the same challenges that confront rehabilitation research generally
  - Identifying precision measurement tools sensitive to the most immediate effect of the intervention
  - Specifying optimal frequency and duration (dose) of the intervention
  - Recruiting and engaging research participants for typically extended periods of time
Other Research Considerations

• Systematic research using a variety of experimental and quasi-experimental designs
• Use of modern measurement development techniques (i.e., item-response theory)
• Rigorous identification of the Minimal Clinically Important Difference (MCID) of these measures
• Comparative effectiveness trials using adaptive experimental designs may be most useful in identifying the active ingredients of studied interventions.
References


