



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

[Kreutzer et al. 1994; Kolakowsky-Hayner & Kishore 1999; Marsh et al 2002; Hanks et al 2007; Godwin et al, 2013]

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

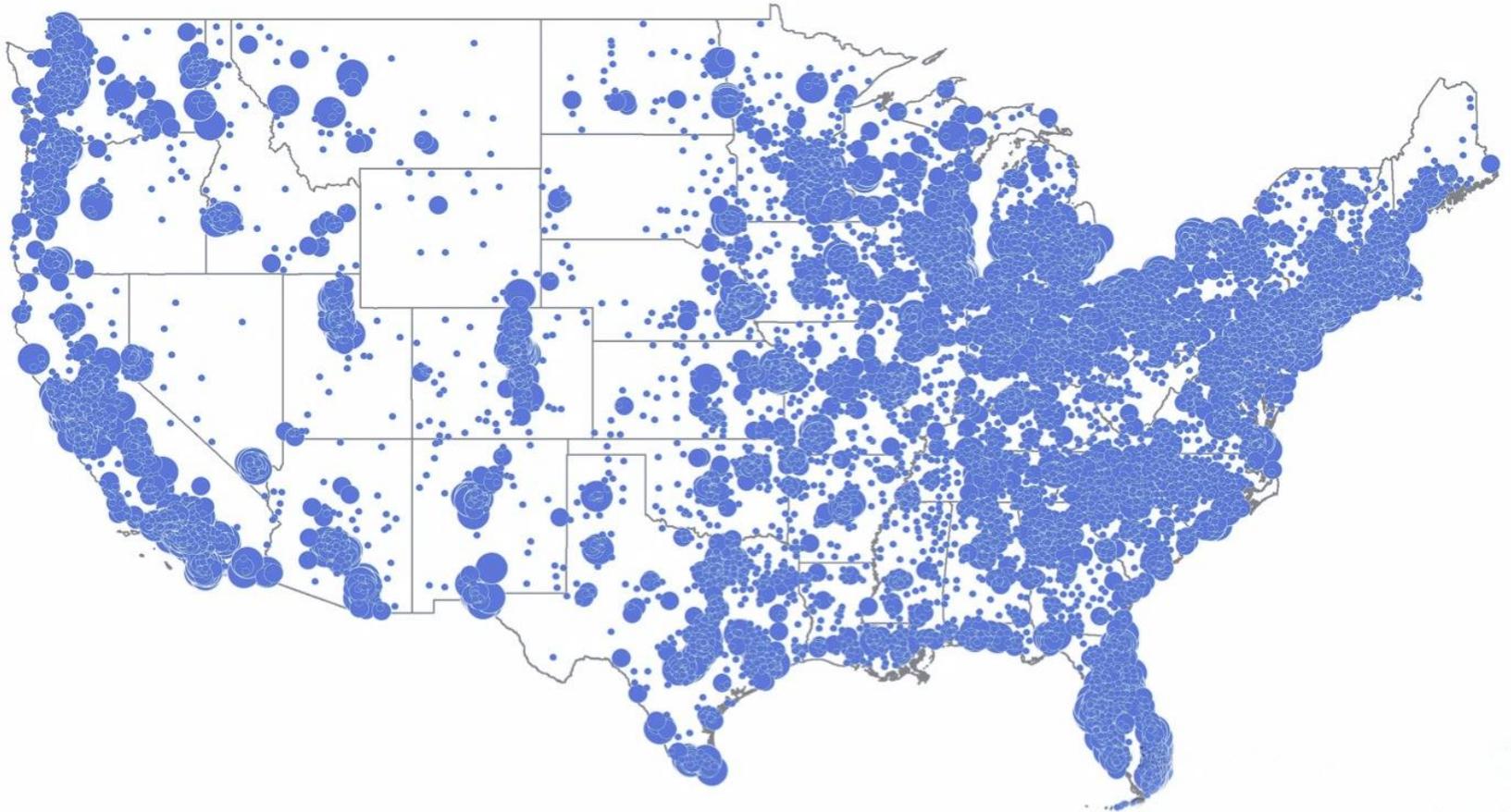
- Sander et al (2003): 25-33% of families are already in significant distress when a family member sustains a TBI
- Family Assessment Device (FAD; Epstein et al, 2006) Global Index aids in triage
 - ✓ A proportion of these may need intensive family therapy or “divorce” from identified patient
 - ✓ Majority will benefit from coping skills/prevention approach

Ramchand et al. 2014



THE RAND STUDY

RAND National Survey of Caregivers



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)

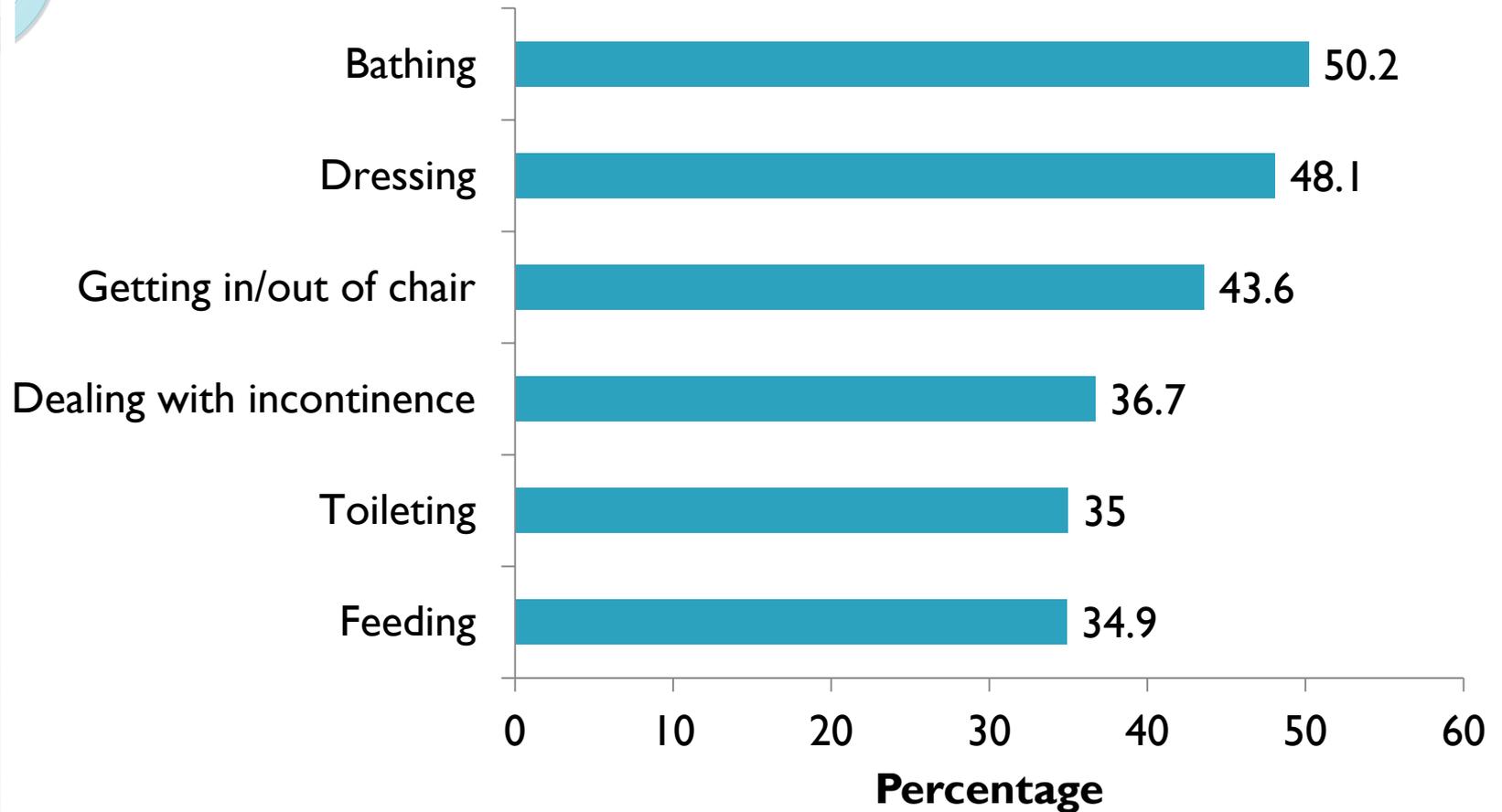
- Likely to be a related to care recipient
 - ✓ Spouse (29%)
 - ✓ Parent (24%)
 - ✓ Other family (24%)
- Mostly female (60%)
- Likely living with care recipient (55%)
- Rely on a caregiving network (67%)
- Serving in role for more than 3 years (63%)
- Just over a quarter support a veteran with TBI (28%)

The Rand Study

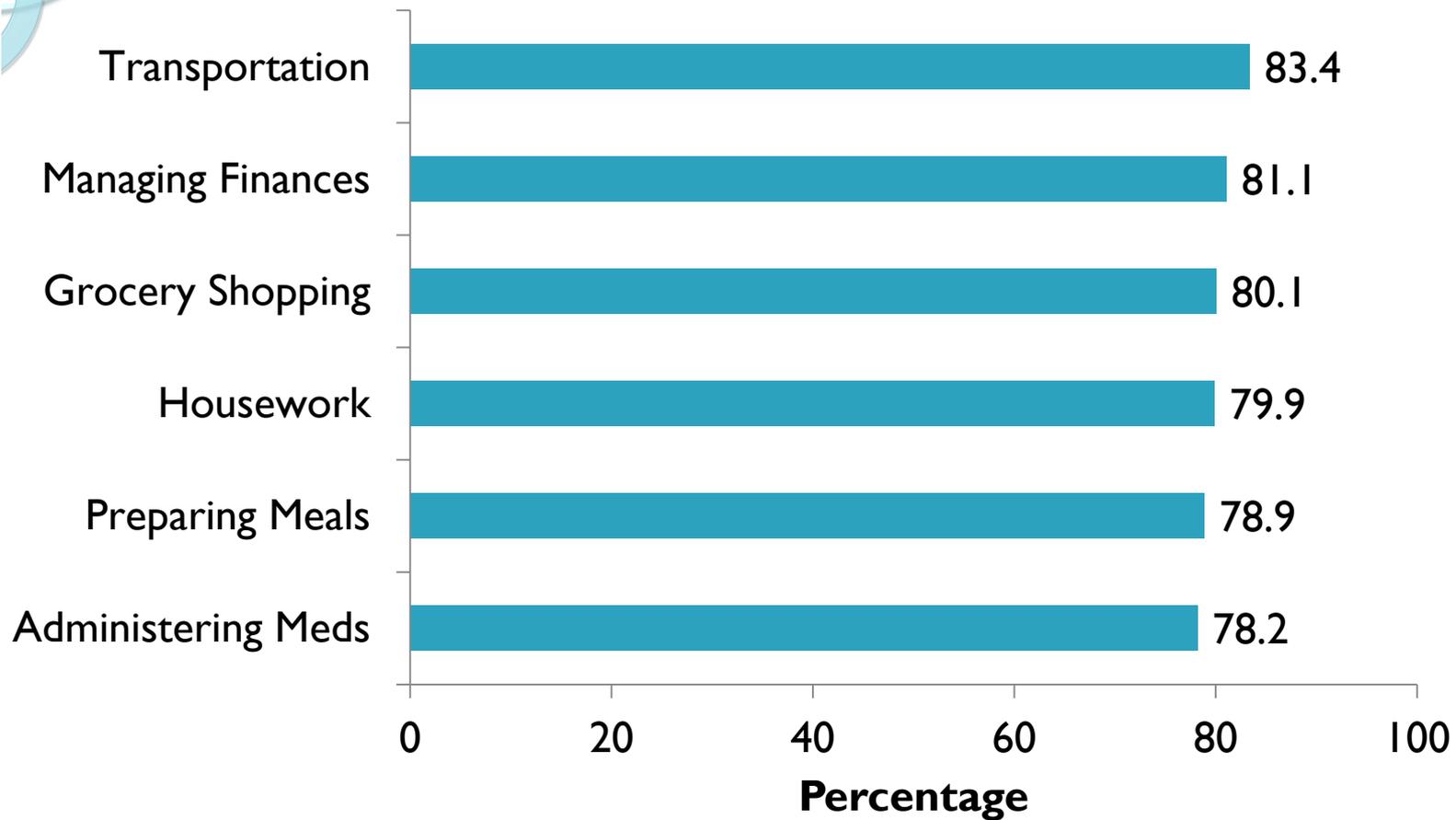


CAREGIVING DUTIES

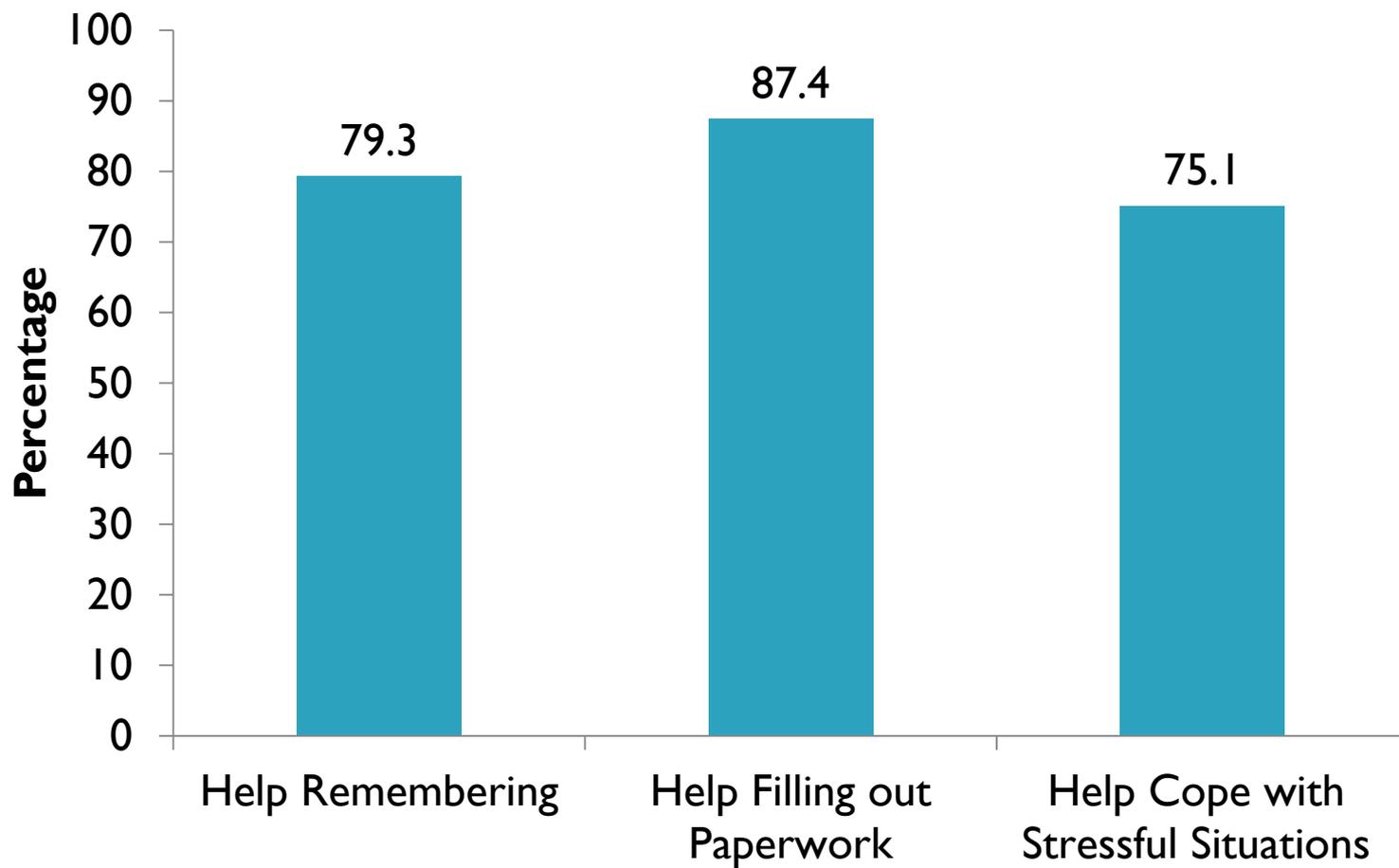
ADLs Performed by TBI Caregivers



IADLs Performed by TBI Caregivers



Other Tasks Performed by TBI Caregivers

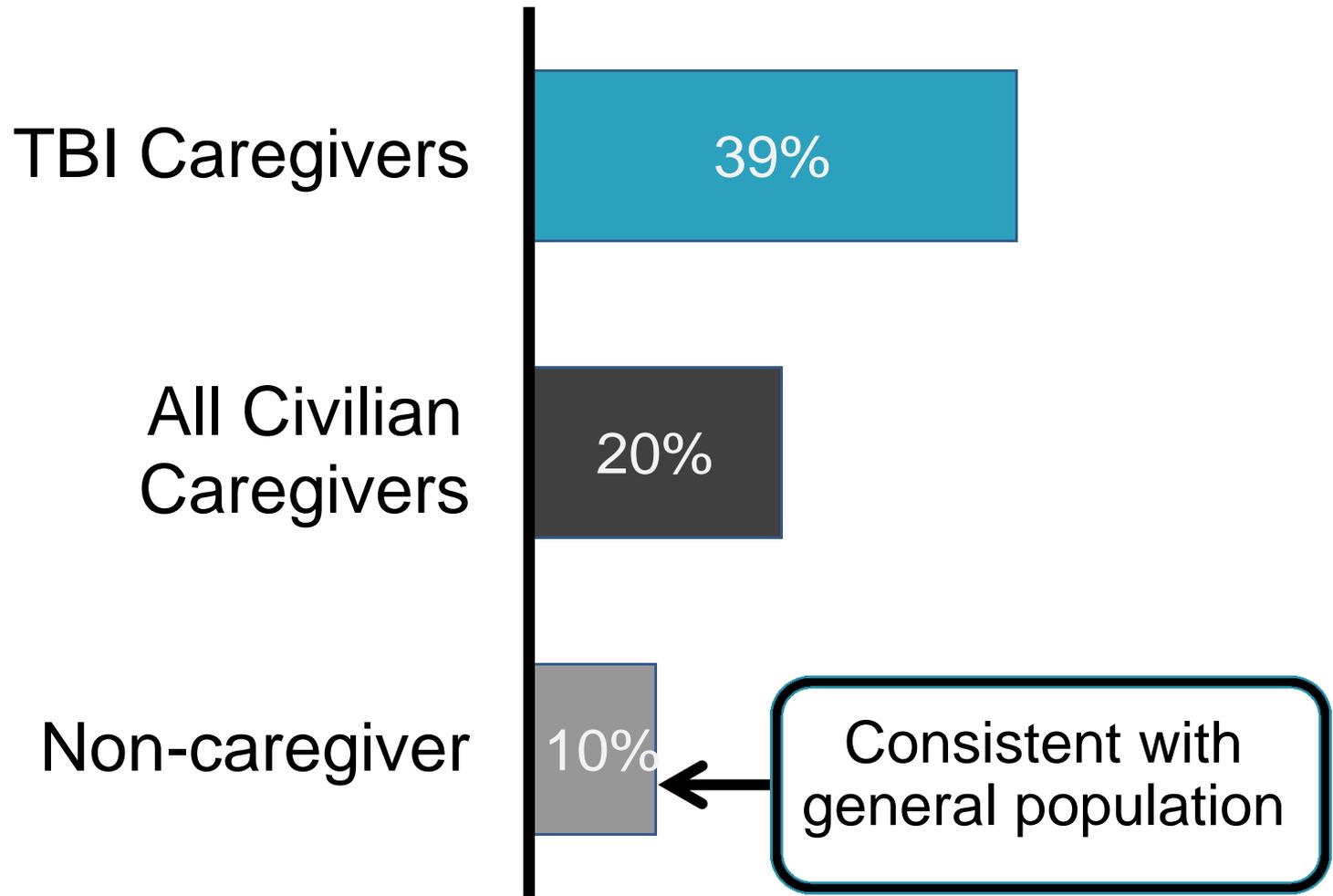


The Rand Study

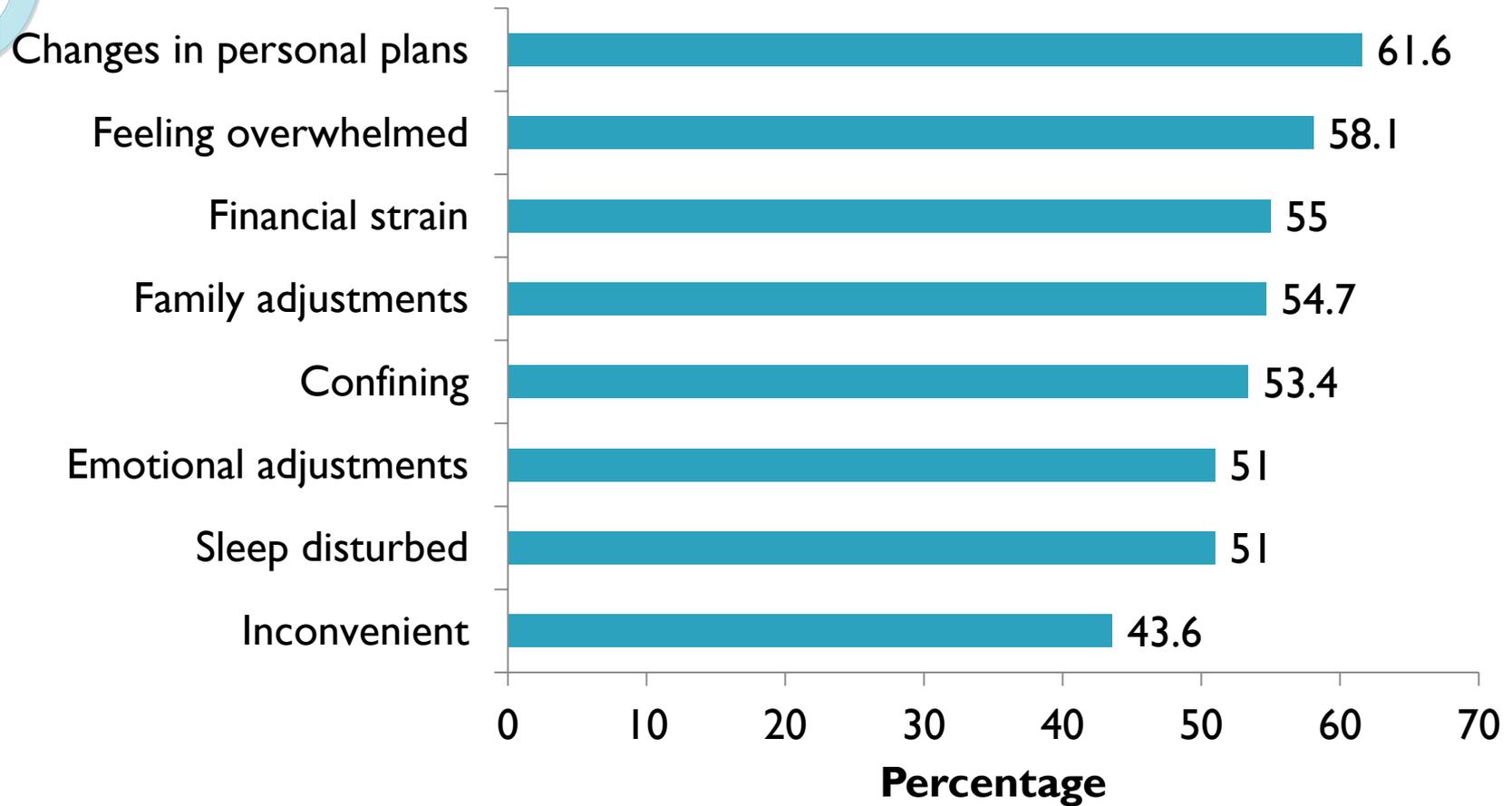


CAREGIVING BURDEN

% of caregivers meeting criteria for probable depression



Other Self Reported Adverse Impacts





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]

VA CARES Evaluation of the Program of Comprehensive Assistance for Family

Caregivers [Preliminary Results, Sperber, Van Houtven et al. unpublished]

- 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)

[Backhaus et al, 2010, 2012, 2015]

- Includes both identified individuals with ABI and families
- Education, CBT coping skills training, and support
- 16 sessions
- Treatment manual available

BICS Studies

- 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



**RESEARCH GAPS,
CONSIDERATIONS,
AND IMPLICATIONS**

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

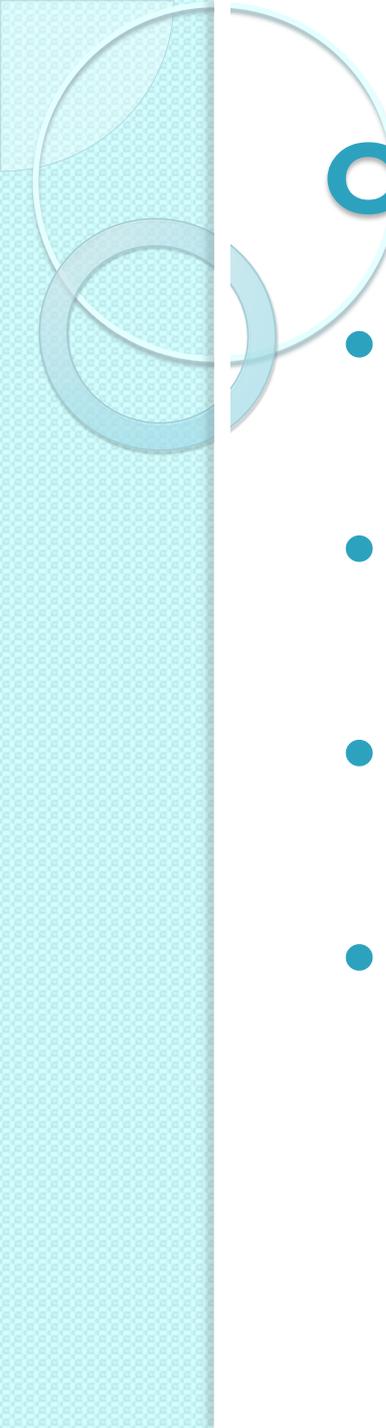
- Understanding the dynamic nature of caregiving
 - ✓ Longitudinal studies of caregivers (with appropriate comparison groups)
- Efficacy and effectiveness of various programs and interventions on caregiver well-being and TBI outcomes
- Telehealth/web-based interventions
- Further evaluation of more specialized 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.

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