

Polytrauma and Blast Related Injuries: Systems of Care and Challenges for Families

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Background

- New legislation to help caregivers (Caregivers and Veterans Omnibus Health Services Act of 2010, Public Law 111-163)
 - Monthly financial payments for those providing direct care to injured Operation Enduring Freedom(OEF)/Operation Iraqi Freedom (OIF) service members who are unable *to perform one or more activities of daily living or in need for supervision or protection.*
 - Training and education, counseling and mental health services, and respite care (including 24-hour, in-home respite care)

Polytrauma Rehabilitation Centers



Richmond



Tampa



Palo Alto



Minneapolis

What we do know about caregivers?

- Advocates for quality and safety
- The constant across the transitions in health care
- Highly engaged/involved from soon after injury
- Critical in helping veterans get and use health care services
- Patients (and families) are younger than other VA patients using rehab services.



Gaps in knowledge:

Little is known about caregivers of polytrauma patients, especially *AFTER* discharge from inpatient rehabilitation:

- Who is providing informal, unpaid care
- How much care is needed
- What kind of care is typically required
- How do the challenges of caregiving affect caregiver health, patient health and rehabilitation, and families in the short and long term.
- How do we prepare family caregivers for their role
- What are the most appropriate intervention objectives to support caregivers.



Study objectives:

Describe:

- Who is providing care
- Caregiver's burden of care (# of hours per week)
- The type of care provided



METHODS

Design:

- Cross-sectional, mixed-methods study of family members of OEF/OIF era injured service members with Traumatic Brain Injury (TBI)/Polytrauma.
- Eligibility included caregivers of ALL patients discharged at least 3 months from PRC from 2001-2009.
- Family members identified through patient records.

Measures

Caregiver information

- Caregiver background characteristics
- Objective burden (what and how much care is provided)

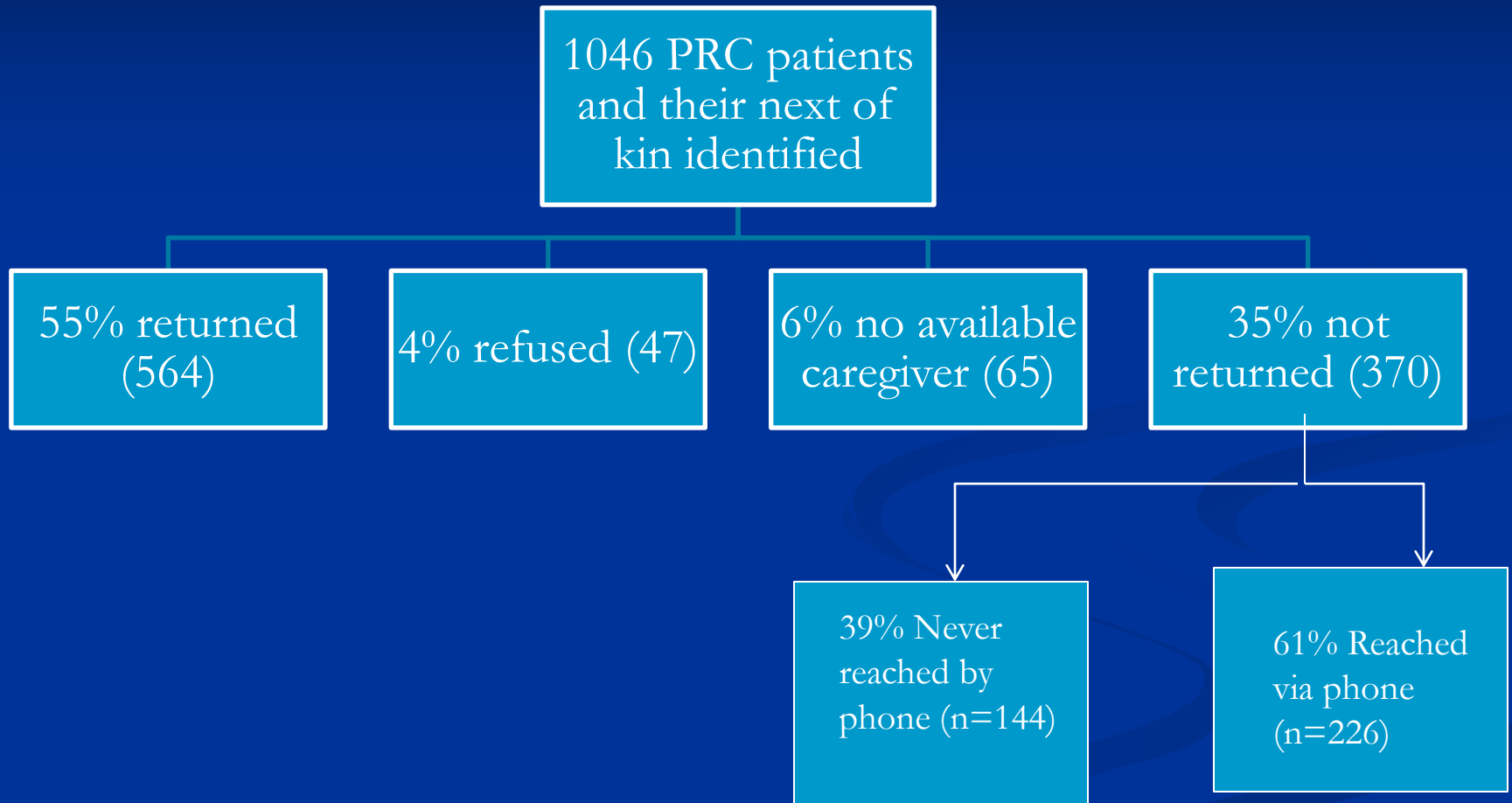
Caregiver proxy reports

about care recipient

- Care recipient background characteristics
- Care recipient injury information

RESULTS

Response Rates

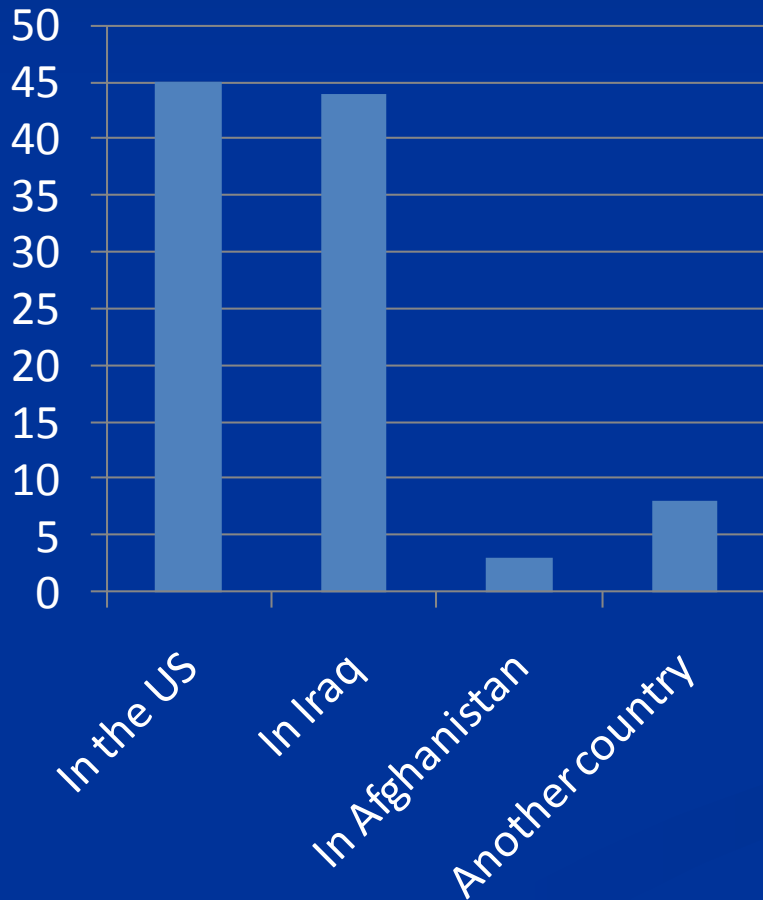


Care recipient demographics

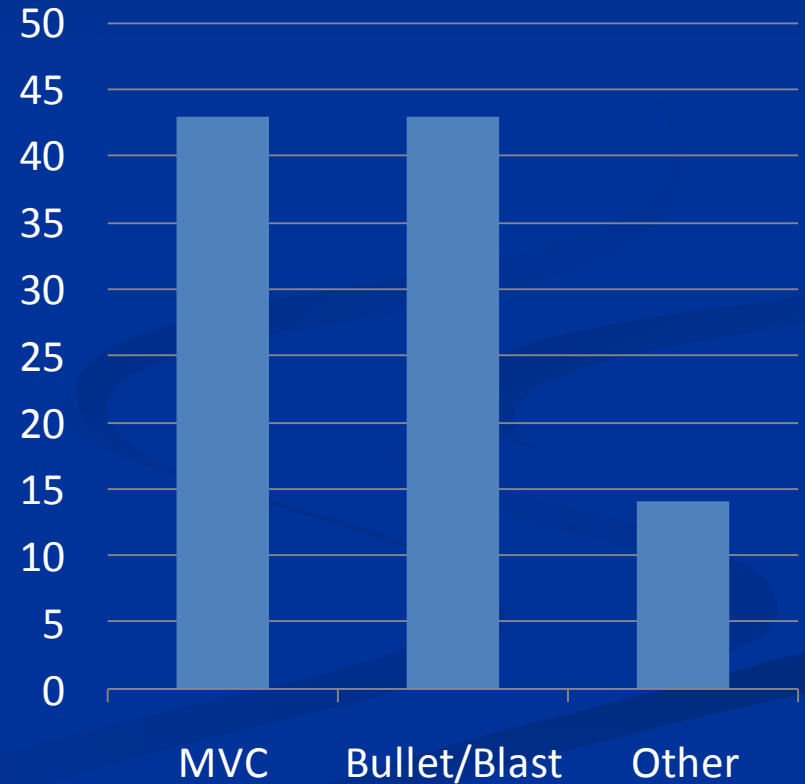
Demographic (n=564)	%
Age (median)	30.5 (range 20-55)
Sex (% male)	95%
Marital status (% married/living with an intimate partner)	47%
Level of education:	
<High school/HS grad	52%
Some college/trade school	38%
Bachelors degree or higher	10%
Employment status	
Employed for wages, attending school, or awaiting medical discharge from military	50%
Neither employed nor attending school	50%

Place and Causes of Care Recipient's Injuries

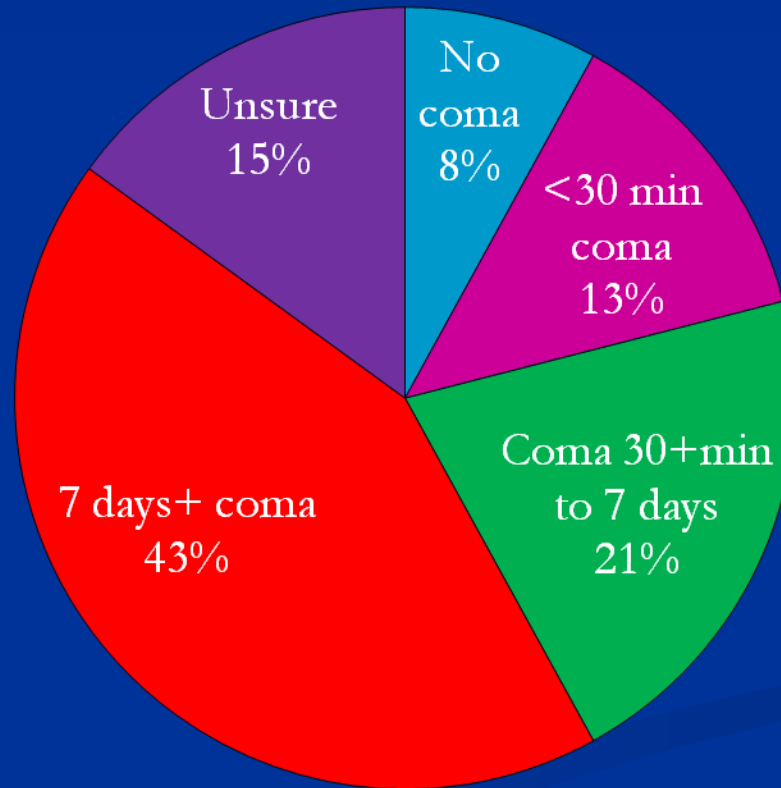
Place of injury



Cause of injury



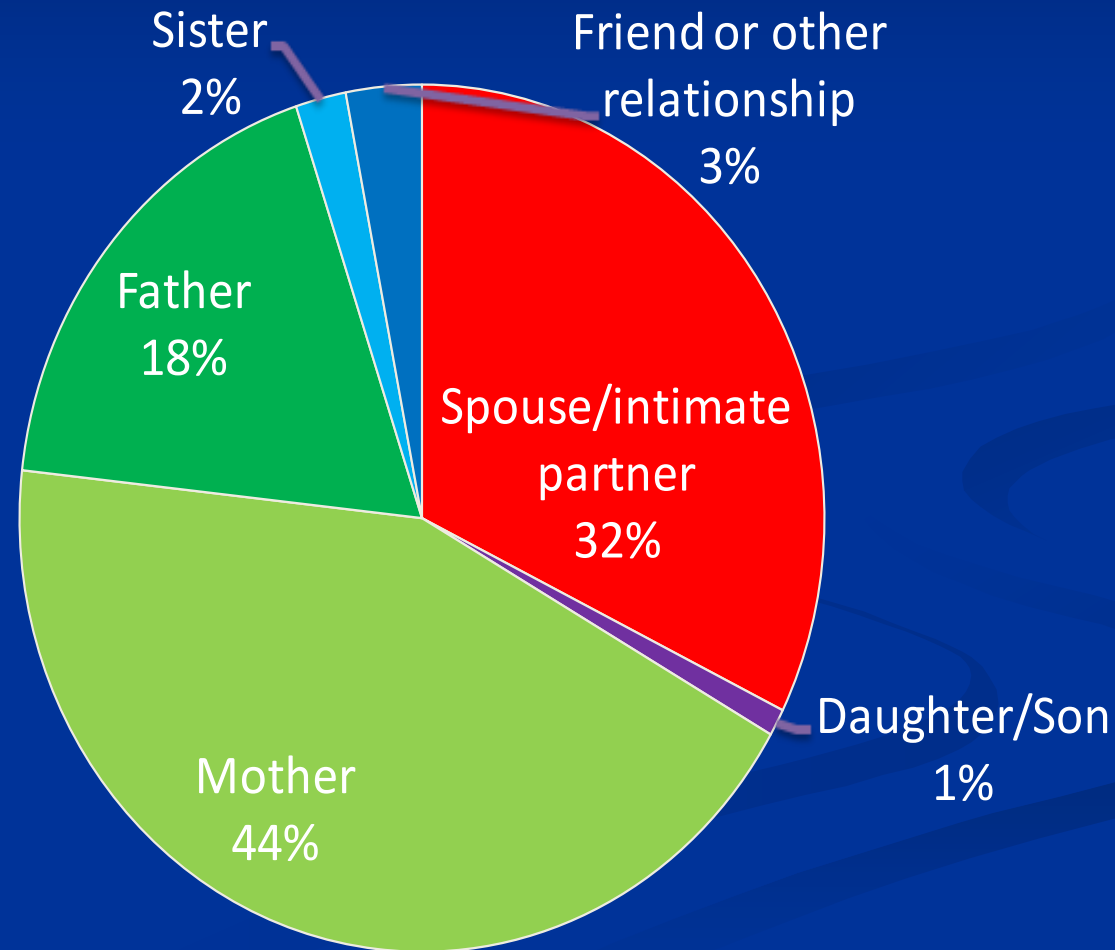
Severity of injuries (loss of consciousness)



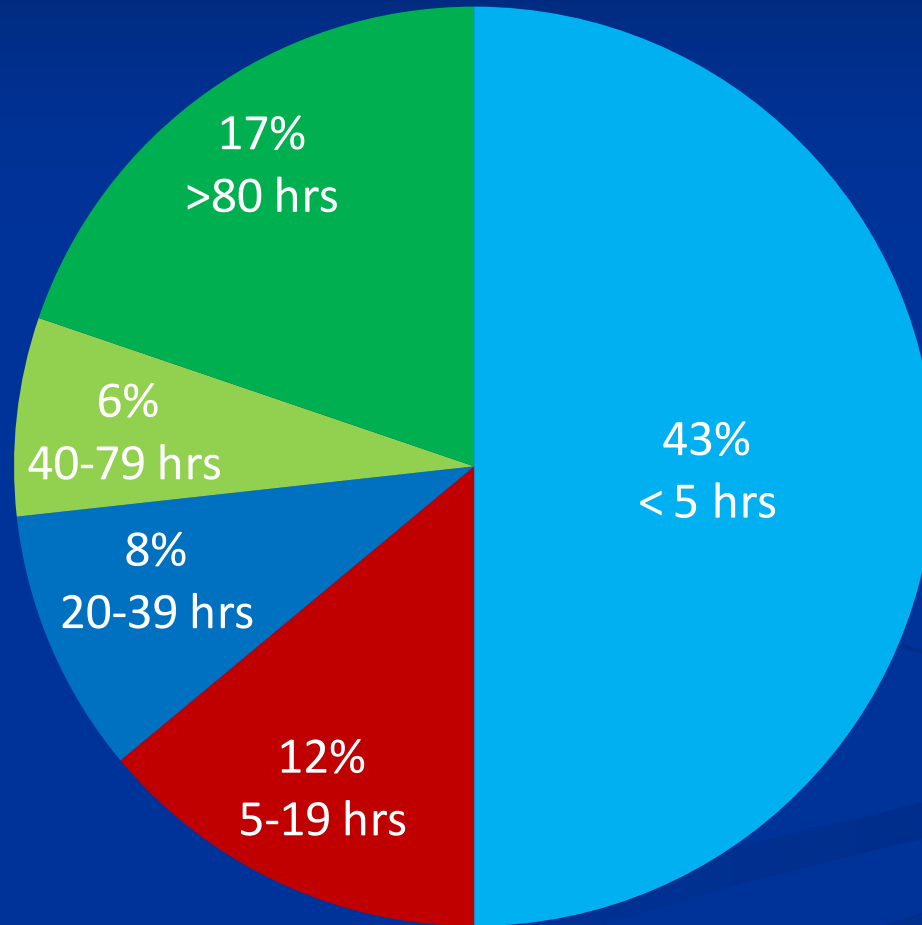
Caregiver demographics

Demographic (n=564)	%
Age (mean)	48 (range 19-82)
Sex (% female)	79%
Marital status (%married/living together)	77%
Level of education:	
<High school/HS grad	27%
Some college or trade school	46%
Bachelors degree	27%
Race (% white)	81%
Ethnicity (% Latino/Hispanic)	12%
Current individual annual income (n,%)	
\$10K or less	31%
\$10K-\$20K	13%
\$20K-\$40K	24%
More than \$40K	32%

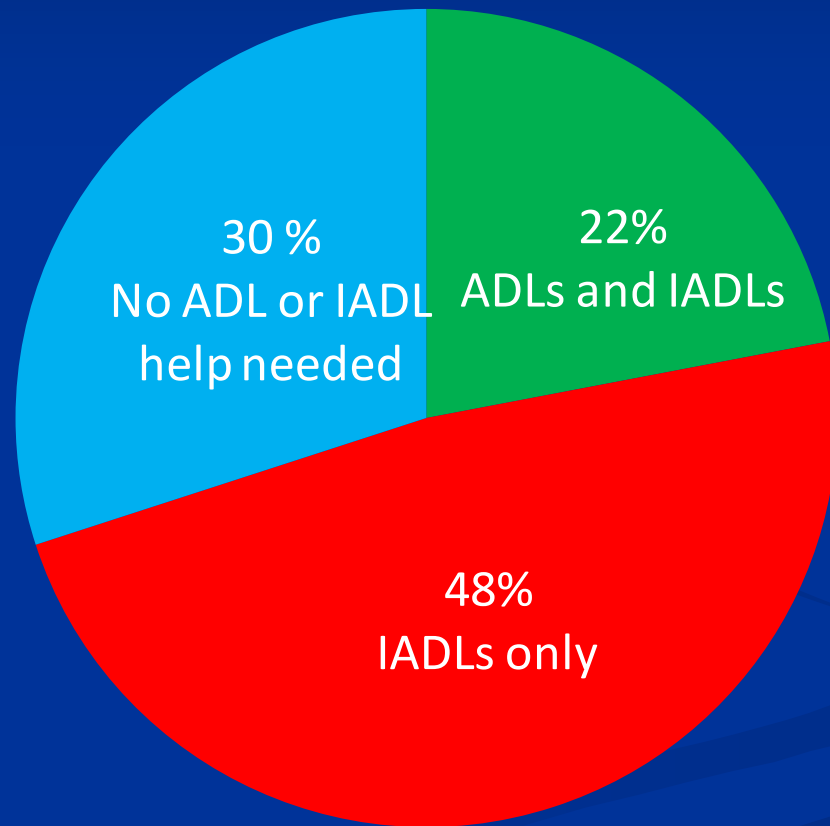
Caregiver's relationship to care recipient (CR)



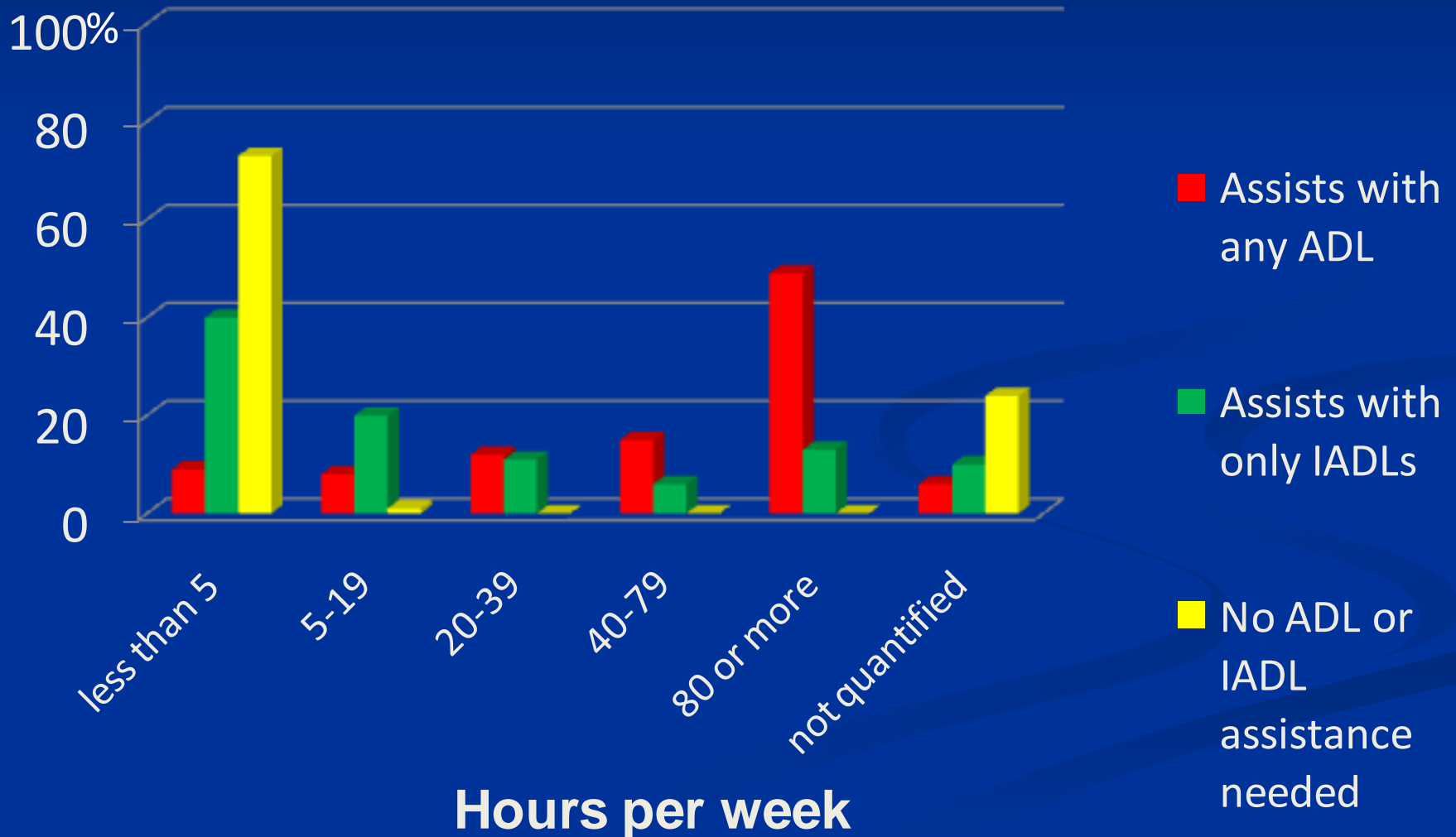
Caregiver Burden: How many hours per week?



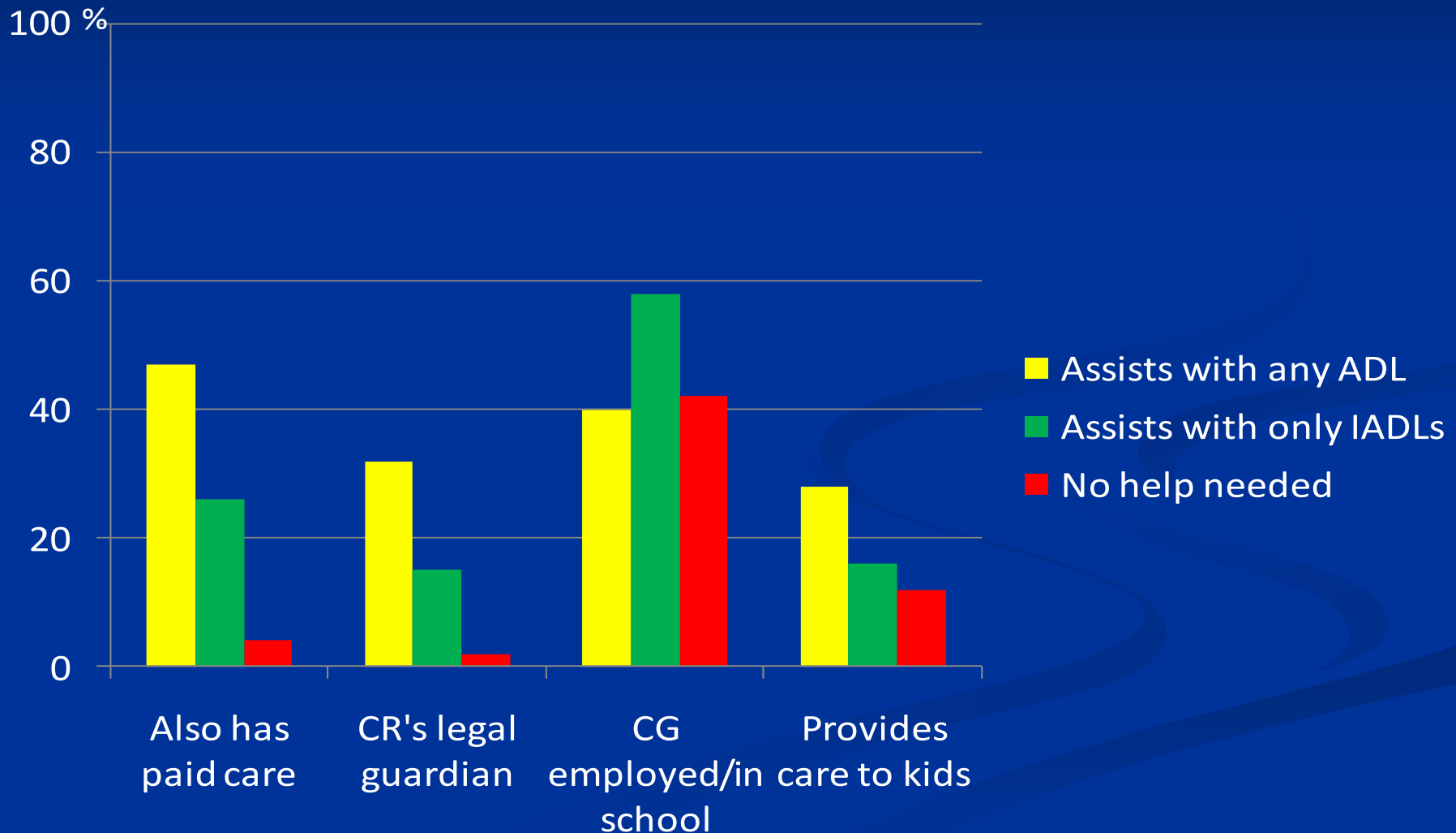
Tasks provided by caregivers



Type of care task provided by number of hours per week spent caregiving



Additional caregiver responsibilities by level of care provided



Additional supportive tasks

Additional IADLs (n=564)	Caregiver provides	No help needed
Supporting/managing CR emotions or feelings	76%	24%
Navigating health insurance system/paperwork	59%	41%
Helping CR with legal issues	58%	42%
Navigating the VA or DOD benefits system/paperwork	58%	42%
Navigating the medical system for CR	56%	44%
Making medical appointments for CR	48%	52%
Helping CR manage pain	40%	60%
Helping CR with therapy (occupational, speech, or physical therapy)	40%	60%
Helping CR with assistive devices (palm pilots, hearing, language, memory aids)	37%	63%

CONCLUSIONS

Study conclusions

- Majority of caregivers are either parents or spouses.
- Nearly 25% spend the equivalent of a 40 hour work week providing care. Another 20% work 5-40 hours a week on caregiving tasks.
- Injured service members needs vary widely.
 - Nearly 30% no longer require care.
 - Nearly 50% require routine assistance with IADLs.
 - 20% need direct care daily (ADLs).
 - Of those needing assistance with ADLs, nearly 50% of the caregivers are working 80 hours or more a week to provide that care.

Study conclusions

- Many of those with the greatest caregiving burden are also balancing additional roles to caring for the injured service member, including working for pay and caring for children.
- The majority of caregivers report either managing additional aspects of care or providing support beyond traditional IADLs. The most prevalent is managing CR emotions and feeling and navigating health systems.

Conclusions

- Some injured service members no longer need traditional forms of care. Some need a significant amount of care. The majority, however, need ongoing assistance in order to be independent. **The new caregiving legislation will not likely help these families.**
- Caregivers have other time-consuming responsibilities in addition to caregiving.
- Most family caregivers provide different forms of ongoing care that are not typically captured.

Thank you!
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