

Family and Caregiver Experiences with Polytrauma: Preliminary findings from the FACES study

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I have no financial conflict of interests associated with this research or presentation.

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Outline

1. Polytrauma system of care
2. Study objectives
3. Preliminary results
 - Who are the survivors?
 - Who are the caregivers?
 - What do caregivers do?
 - How has providing care affected their life?
4. Conclusions
5. Future contributions

Polytrauma system of care

Definition of Polytrauma: Injuries and impairments to multiple body systems or organs (e.g., traumatic brain injury, amputation, burns, vision loss,).



Background

Little is known about caregivers of PT 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 the physical, emotional and financial burden (and rewards) of caregiving and the resources available to caregivers.
- Definition: anything that you do for the person you are helping that you wouldn't be doing if they had not been injured.



METHODS

Design:

- Cross-sectional study of family members of OEF/OIF injured service members with TBI/Polytrauma.
- Eligibility included primary caregivers of ALL injured service members (survivors) discharged at least 3 months from TBI rehab/PRC from 2001-2009.
- Family members identified through patient records.

Design:

Quantitative
Data and Results



Qualitative
Data and Results

Cross-sectional mailed survey

Population

Identified caregivers of ALL patients discharged at least 3 months from a PRC from 2001-2009.

In-depth interviews

Sample:

16 purposively-chosen caregivers who participated in the mailed survey.



Design:

- Surveys were mailed to patient's next of kin.
- Nomination forms were included in case the person contacted did not consider him/herself to be the primary caregiver.
- Phone calls were made to caregiver 14 days following first mailing to answer questions.
- Second mailing, via Fed Ex, was sent to non-responders 21 days after the first mailing.
- Final phone call to non-responders was attempted 28 days after first mailing.

Measures

Caregiver information

- **Caregiver background characteristics**
- **Objective burden (what and how much care is provided)**
- **Subjective burden (strain from providing care)**
- **Role strain**
- **Financial strain**
- Caregiver health, including depression, anxiety, functioning
- Social support for caregiver
- Caregiver report of stigma from injuries
- Caregiver report from stigma of providing care
- Caregiver self-efficacy
- Positive gains from caregiving
- Family functioning
- Family conflict

Caregiver proxy reports about survivors

- survivor background characteristics
- survivor health, including neurobehavioral symptoms and ongoing health conditions
- survivor integration into the community

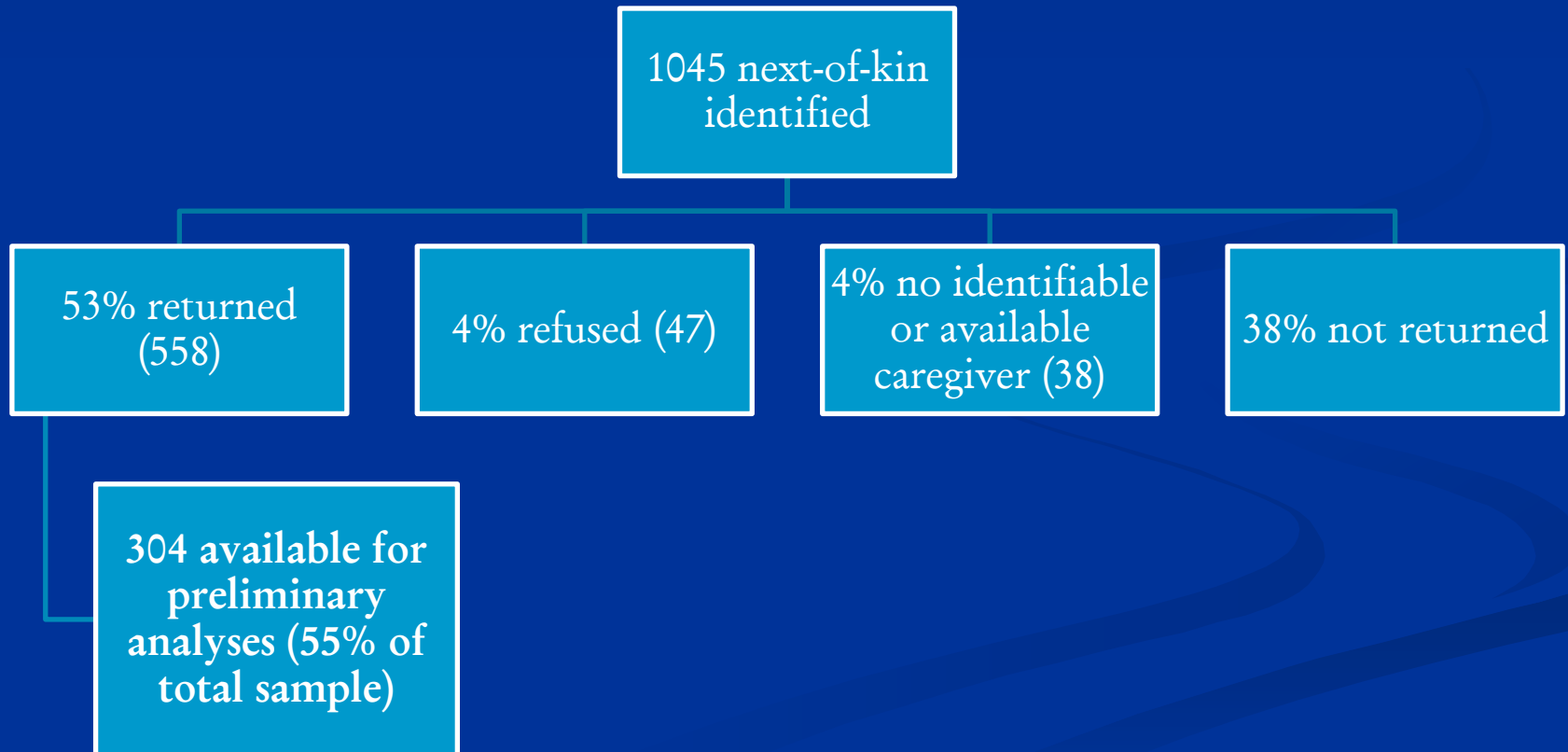
Caregiver Burden

- **Objective burden**
 - Number of days providing care
 - Number of hours a day when providing care
- **Subjective burden (Zarit Burden Inventory)**
 - Caregiver report of the physical, emotional and financial toll of caregiving
- **Role Strain**
 - Strain resulting from competing demands, expectations, or obligations of multiple roles
- **Financial Strain**
 - Financial distress due to the costs of caregiving

PRELIMINARY RESULTS

Response Rates

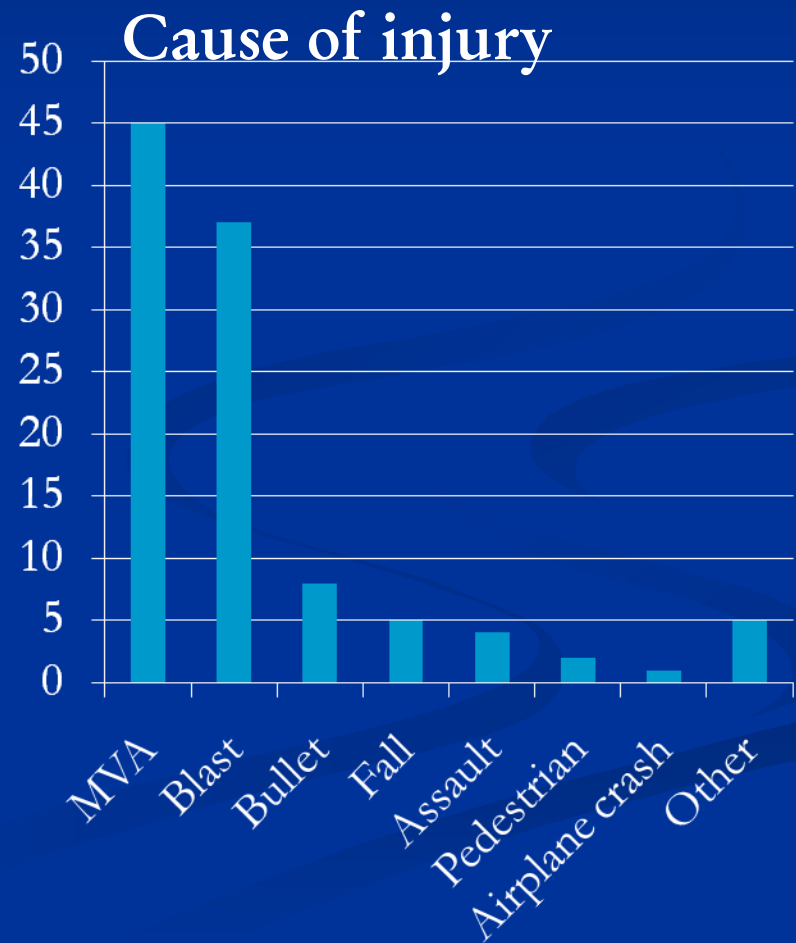
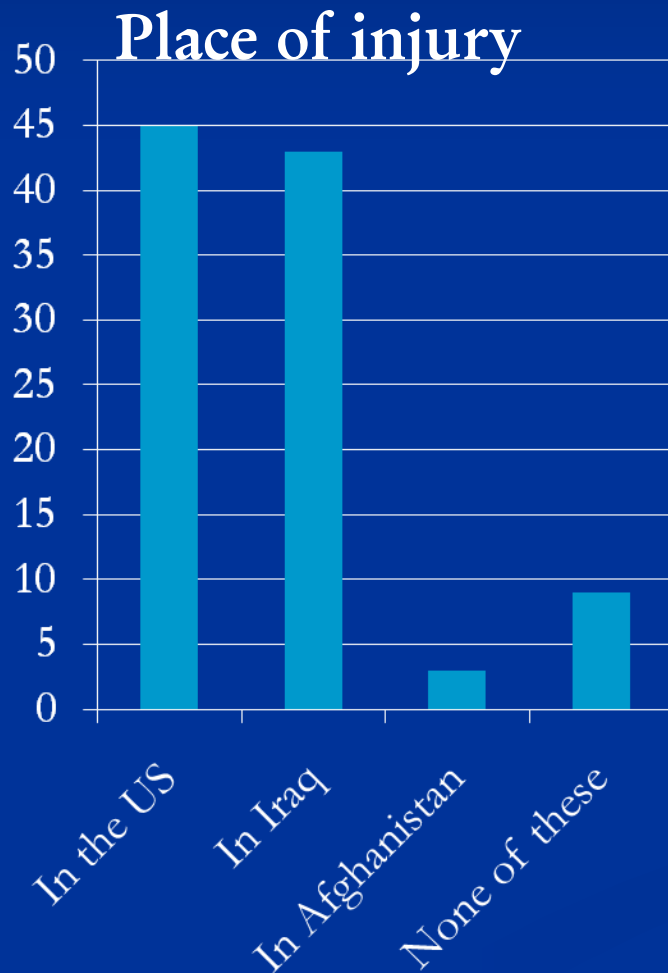
Last day of data collection: December 1, 2009



Survivor Demographics

| Demographic (n = 311) | % |
|--|------------------|
| Age (median) | 28 (range 20-53) |
| Sex (% male) | 95% |
| Marital status (% married/living with an intimate partner) | 48% |
| Level of education: | |
| < High school | < 1% |
| High school graduate | 50% |
| Some college | 28% |
| Business, vocational, trade school | 12% |
| Bachelors degree | 8% |
| Master's or Doctoral degree | 2% |

Place and Causes of Survivor 's Injuries



Types of injuries reported (in order of prevalence)

TBI—100%

Fractures—47%

Injuries to the face (including eyes, ears, nose)—37%

Wounds—35%

Injuries to internal organs (respiratory, gastrointestinal)—17%

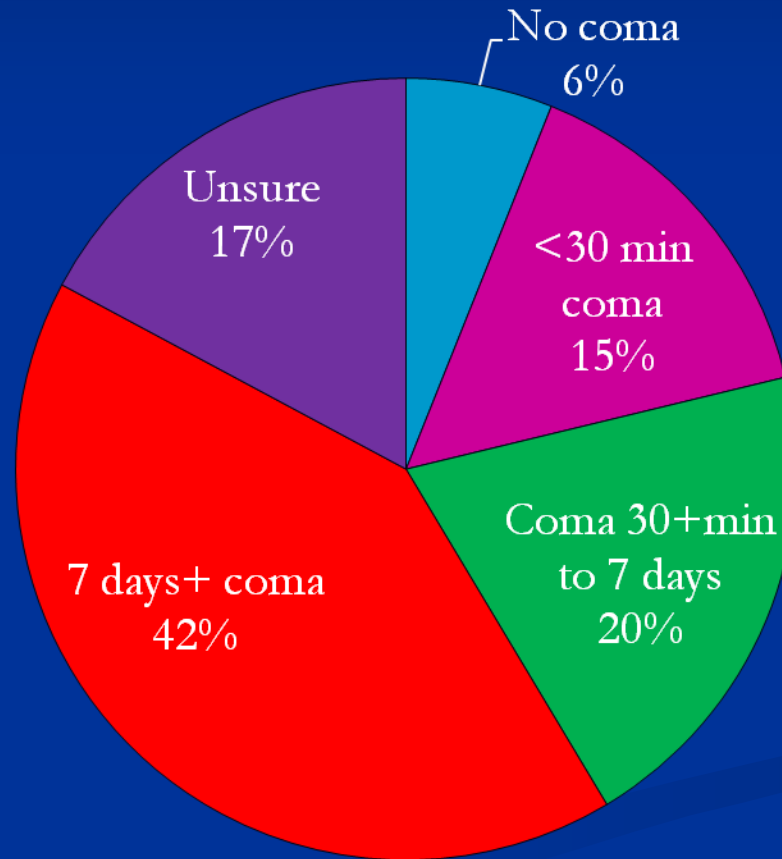
Spinal cord injury—11%

Burns—7%

Amputation—5%

Other—18%

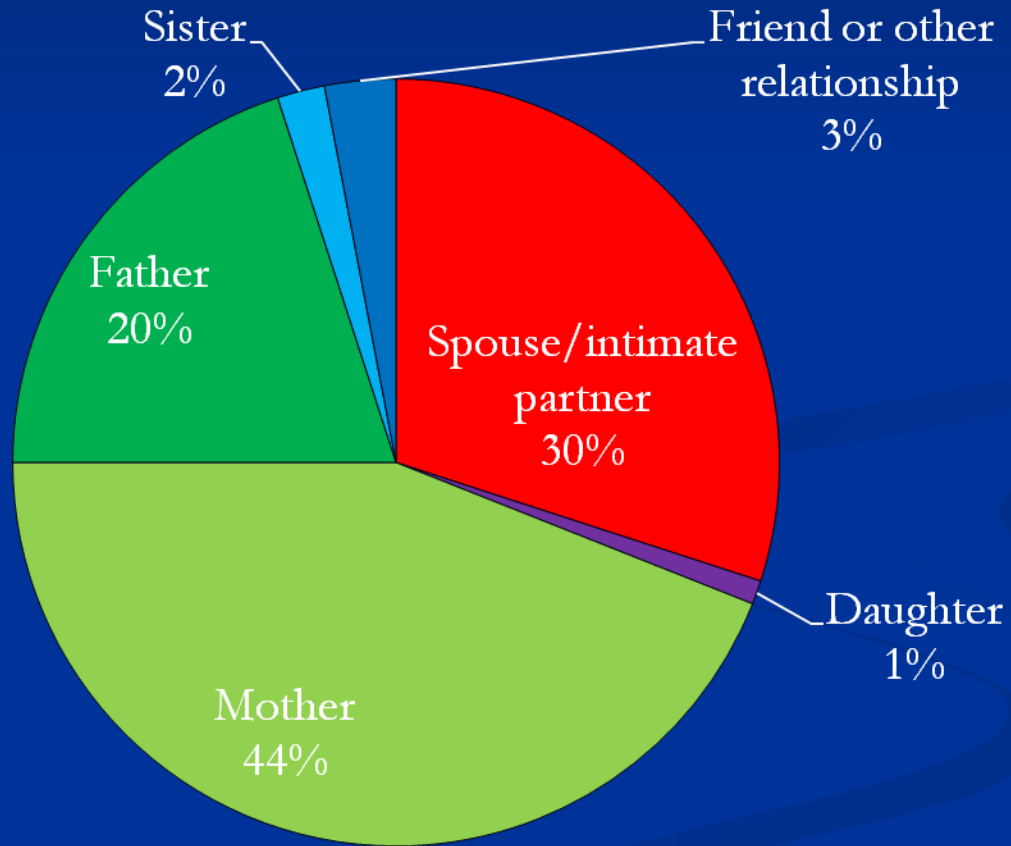
Severity of injuries (loss of consciousness)



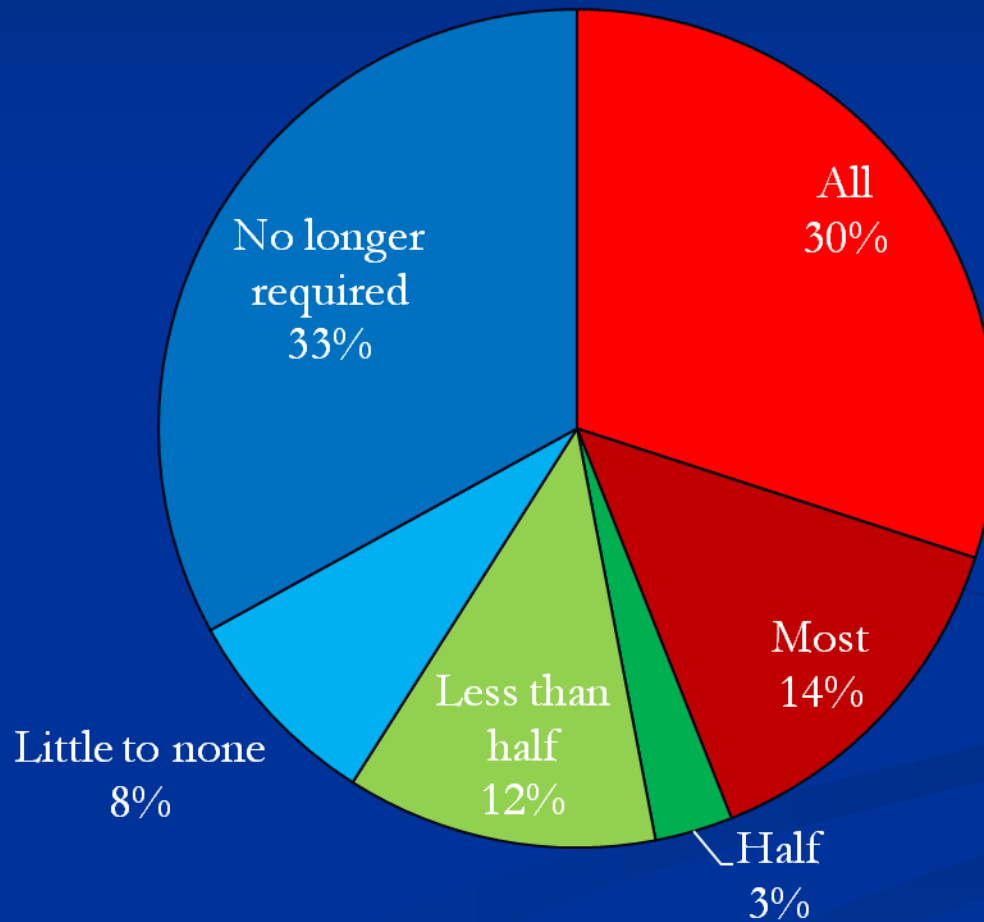
Caregiver demographics

| Demographic (n = 311) | % |
|--|------------------|
| Age (mean) | 48 (range 19-82) |
| Sex (% female) | 79% |
| Marital status (% married) | 70% |
| Level of education: | |
| < High school | 6% |
| High school graduate | 23% |
| Some college | 30% |
| Business, vocational, trade school | 14% |
| Bachelors degree | 18% |
| Master's or Doctoral degree | 9% |
| Race (% white) | 84% |
| Ethnicity (% Latino/Hispanic) | 10% |

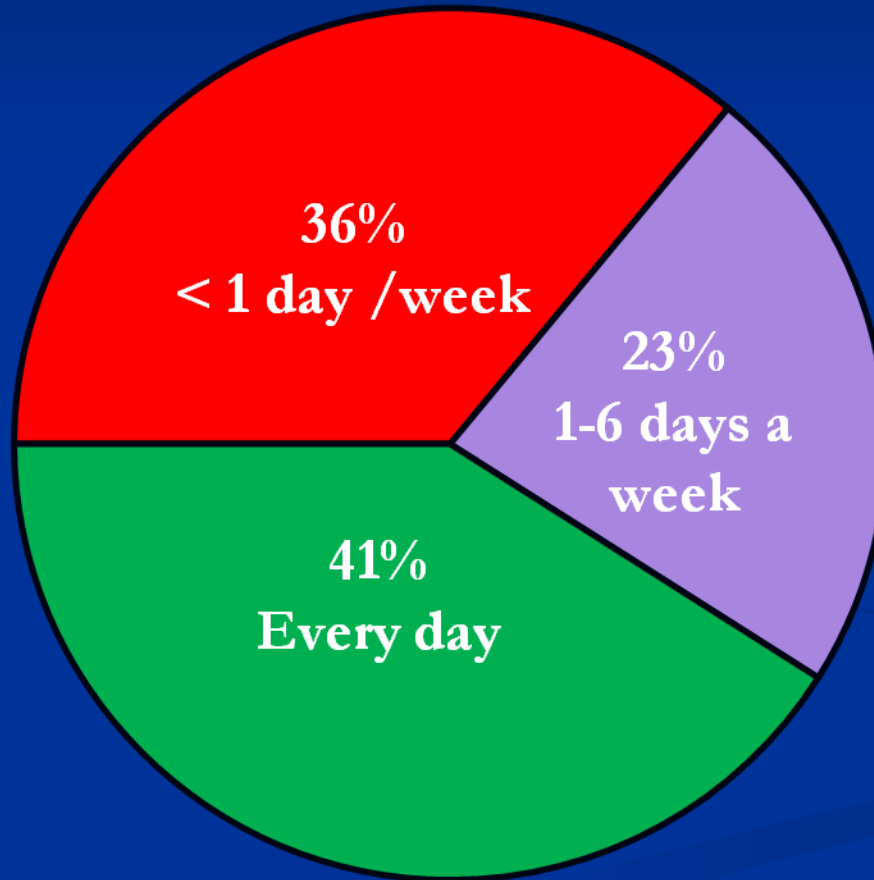
Caregiver's relationship to survivor



Given all the survivor's needs, how much of that care do you provide?

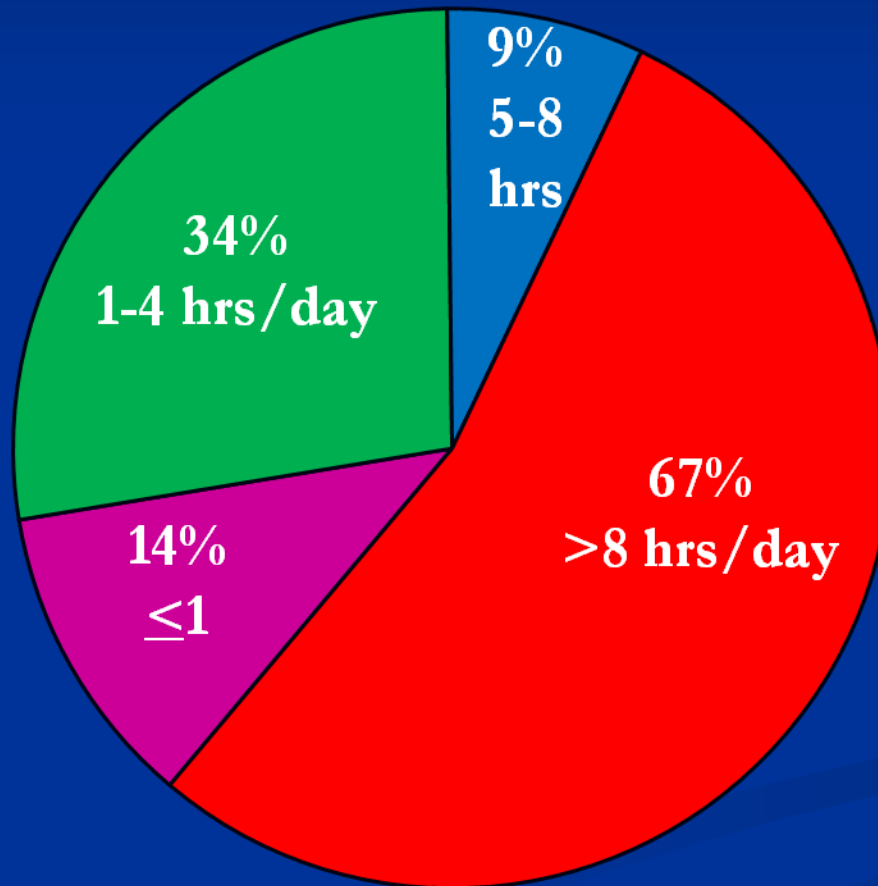


Caregiver Burden: How many days a week*?



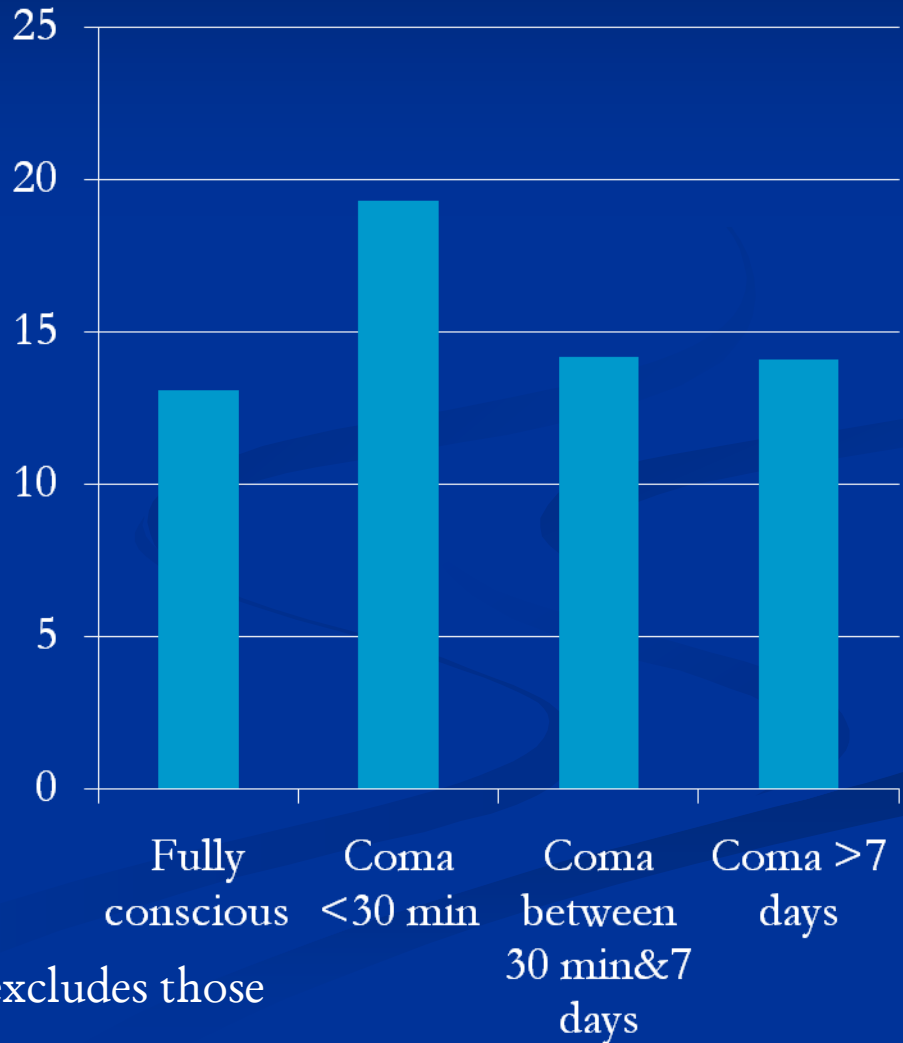
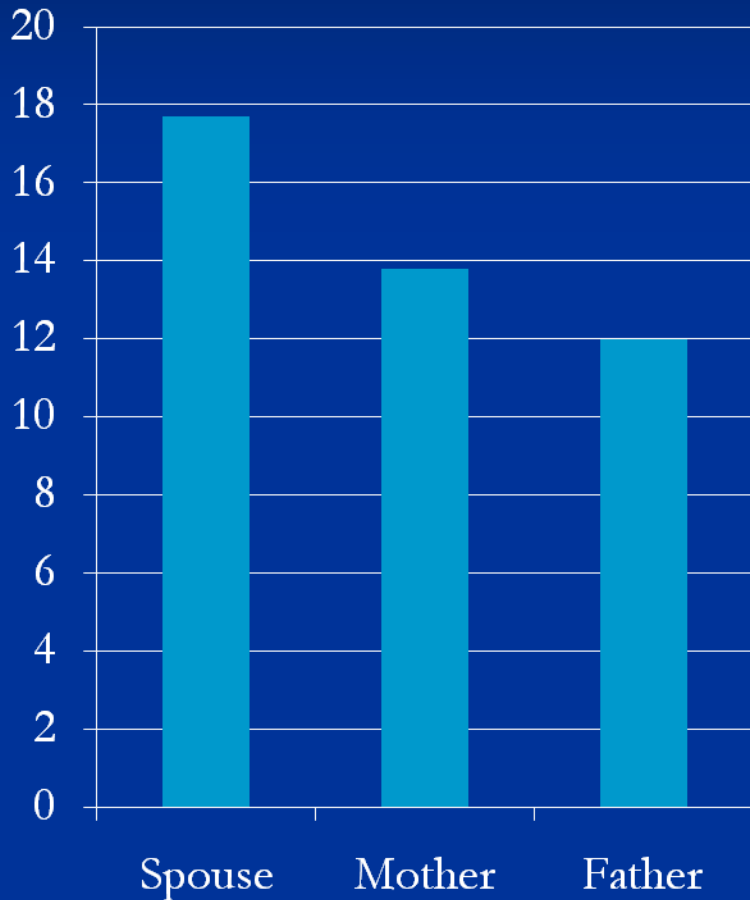
*excludes those whose survivor no longer requires care

Caregiver Burden: How many hours a days*?



*excludes those whose survivor no longer requires care

Caregiver Burden* by kinship and severity of injury



*measured using the Zarit Burden Inventory, excludes those whose survivor no longer requires care

Caregiver Burden Role Strain

- 59% reported currently working for pay
- 25% reported caring for another family member or young children at home
- 12% had primary parenting responsibility or also cared for another family member & also work for pay in addition to the caring for the survivor.

Caregiver Burden Role Strain

Of those caregivers who worked:

- 22% reported no role strain at all
- 36% scored in the top 50% on an index tapping the degree of role strain* resulting from conflict between caregiving and work demands.

* 3-item index, difficulty balancing work and caregiving, work interferes with caregiving, caregiving interferes with work .

Caregiver Financial Strain

- 49% have stopped working or reduced their hours for pay since the injury.
- 56% of those who are not currently working report that the reason is in order to care for the survivor.
- 59% report using their savings in order to help pay the costs of caring.
- 11% report using money from retirement accounts to help pay for care.

PRELIMINARY CONCLUSIONS

Good news

- One-third of family members surveyed report that the survivor no longer requires care.

Burden of care

- Nearly a third of those surveyed are providing all the care, with little help.
- 40% are providing care every day
- Almost 70% are providing more than 8 hours of work/day when they provide care.
- Caregivers are quitting work, reducing hours for pay and using their own financial resources in order to pay for care.
- Caregivers who continue to work often balancing multiple caregiving roles.

Limitations

- Limited data set; full analysis by summer 2009.
- This type of research is methodologically and analytically complex.
 - Caregiving is often shared. We have reports only from primary caregiver.
 - Trajectories of care have not yet been examined.
 - Caregivers change over time.

Future Contributions

Do caregiver factors significantly affect community integration of survivors?

This study may allow for estimation of the impact of caregiver factors on survivor outcomes, independent of injury characteristics and survivor characteristics.

In addition, we will examine the relationship of caregiving on caregiver and survivor health outcomes.

Thank you!