


Families of Rural OEF/OIF Veterans with TBI: Concerns and Issues

Linda Olivia Nichols, PhD

Health Services Researcher, VA Medical Center, Memphis
Professor, Preventive and Internal Medicine, University of
Tennessee Health Science Center



Objective for Today

- Discuss findings that illustrate challenges of working with mild-moderate TBI caregivers and families
-



Study

- ❑ Six-month rapid response pilot project, 10/08 to 4/09
- ❑ 6 rural TBI families, all Guard
- ❑ Mild to moderate TBI, 1-5 years post injury
- ❑ Co-morbid PTSD, paranoia
- ❑ Qualitative methodology
- ❑ Explore expanding support from community volunteers for TBI families



Findings

- Substantial need of family and patient for information about condition, prognosis and sequelae
 - Education about what TBI is
 - Problem solving
 - Managing changes
 - Understanding why things happen
 - Unsafe behaviors
 - Frightening behaviors
 - Communication changes
 - Coping – work, finance
 - Grief
-



Findings

- Families are not always ready to hear at diagnosis
 - Homecoming euphoria may mask symptoms
 - Caregiver and patient may be overwhelmed - new diagnosis or information
 - Caregiver and patient may be frightened
 - Ongoing denial or lack of understanding
 - Disease may not have fully manifested
 - Acceptance is not linear
 - Acknowledgement would make it “real”
-



Findings

- Families did not want volunteer community assistance
 - Families did want professional assistance from DoD and VHA
 - Unsure how to navigate DoD and VHA system, especially those on medical hold
 - Complex and changing compensation and pension procedures
 - Unclear about how long care will last
-



Findings

- Families concerned about social, employment and financial repercussions if extent of TBI deficit became known in the community
 - Stigma
 - Privacy
 - Independence
 - Financial security (employment vs. compensation and pension)
-



Significance

- Unsure about the disease
 - Lack of understanding and education
 - Comorbid PTSD
 - Unsure financial future
 - Continue working with deficits “hidden”
 - Uncertainty about compensation and pension
 - Unsure care future
 - New, additional, or evolving symptoms
 - Care limitations – what is and will be offered?
-



Future

- At diagnosis and during care, assess families and patient for readiness to hear
 - Provide risk-based, just-in-time and ongoing, user friendly education for family and patient (in-home, on-line, telephone)
 - Simplify VHA/DoD procedures
 - Institute one point of contact for DoD and VHA
 - Provide community education and strategies to assist family and Veteran for faith/employment/social groups
-