

This article and any supplementary material should be cited as follows:

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## **Appendix. TBI-CareQOL Military Caregiver Focus Group Guide**

### **1. Leader Introductions**

- a) Welcome/Thank you; Lead Facilitator Introduce self/Co-Facilitator, others in the room
- b) Introduce Purpose of Study, Example description: *The goal of this project is to develop a questionnaire about what researchers refer to as the “quality of life” of caregivers of individuals with traumatic brain injury. By “quality of life”, we mean the symptoms, problems, and concerns as well as any benefits, gains, fulfillment, or joys that caregivers have as a direct or indirect result of caring for their loved one with traumatic brain injury. The best way to develop a questionnaire like this is to talk with the caregivers and learn about their experiences caring for their loved ones with traumatic brain injuries. Once we’ve developed this questionnaire it will be used to identify caregiver needs and develop appropriate interventions to assess these needs.*

### **2. Group Ground Rules**

- a) Confidentiality
- b) “Popcorn style” focus group
- c) Remind to focus on caregiver content – facilitators may interject if participants get “off topic”
- d) Everyone’s experience is different – we want to hear it all, there are no right or wrong answers
- e) Tape Recording – try to use first names only
- f) Time limit – we have only 90 minutes, the facilitator’s job is to keep us moving along and make sure we cover a lot of ground.
- g) Special time at the end to talk about access to medical care/services. Please save that discussion as much as possible for the end.

### **3. Participant Introductions**

For example: *“Let’s go around the room and introduce ourselves. Tell us your first name and why you decided to participate in the focus group.”*

### **4. Free List Exercise on Quality of Life**

#### **SAMPLE QUESTIONS:**

- a) *How has being a caregiver affected your quality of life?*
- b) *In what ways has your quality of life changed since becoming a caregiver?*

#### **PROBES:**

- a) *How has being a caregiver affected your relationships? Your social life? Your relationship with the service member, children, friends, other family? Your family life, in general?*
- b) *How has being a caregiver affected your work life? Your finances? Your career?*
- c) *How has being a caregiver affected you physically? Your health?*
- d) *How has being a caregiver affected you emotionally? Possibly probe for: depression, anxiety/worry, guilt, stress, positive emotions.*

#### **ACCESS TO CARE:**

- a) *Tell us about your ability to get the services, programs, or support (i.e. health care, social services, etc.) that you need for yourself.*
- b) *Has the type of services, programs, or support you needed changed over time?*
- c) *What sorts of barriers have you encountered to getting services, programs, or support for yourself?*
- d) *Tell us how it has been arranging for the health care needs of the person you care for?*

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- e) *Have you met with a care coordinator for the person with a TBI? Tell us about your experience with care coordinators.*
- f) *What would be helpful to you, as a caregiver, in terms of arranging/covering/coordinating care for the person with the TBI?*

## **5. Closure**

*“Did these exercises bring to mind any other issues that affect your quality of life?”*

*“Thinking back to our discussion, is there anything else that you would like to comment on now?”*

*“Thank you again for your participation. Your input is invaluable because no one else can tell us what issues are most important for traumatic brain injury caregivers. The quality of life questionnaire that we are creating will be very important in improving the quality of life of individuals with traumatic brain injury and their caregivers.”*