

## UNDERSTANDING HEALTH-RELATED QUALITY OF LIFE IN CARE PARTNERS OF PERSONS WITH TRAUMATIC BRAIN INJURY

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### The TBI-CareQOL Study:

UNDERSTANDING HEALTH-RELATED QUALITY OF LIFE IN CARE PARTNERS OF CIVILIANS AND SERVICE MEMBERS/VETERANS WITH TBI



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### OBJECTIVES

1. Understand recent research efforts to prioritize research (in both civilian and military populations) that focuses on care partners of individuals with TBI.
2. Identify key concepts of health-related quality of life in care partners of individuals with TBI from clinical interviews with care partners of civilians and service members/veterans with TBI of civilian-TBI.
3. Identify health-related quality of life issues in care partners of individuals with TBI using new measurement tools.

## Slide 4

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**FJ11** found in a poster, keep?

Freedman, Jenna, 12/21/2016



### CARE PARTNERS (CIVILIAN AND SMV)

- Caregiver burden is also associated with poorer outcomes for the individuals with the TBI
  - Poorer functional ability
  - Poorer cognition
  - Less psychosocial well-being
  - Less social integration
  - Poorer work productivity and employability
  - Poorer adjustment to disability

### HEALTH-RELATED QUALITY OF LIFE (HRQOL)

- a multidimensional construct that reflects how mental, physical, or social health influence overall health status (Cella, 1995)
- What are the specific aspects of caregiving that contribute to caregivers' HRQOL following TBI?

### WEAKNESSES OF EXISTING CAREGIVER TBI MEASURES

- borrowed from other caregiver populations, (e.g., dementia or multiple sclerosis) and do not capture the unique aspects of caring for an individual with a traumatic injury
- have unknown validity in caregivers of those with TBI
- do not capture the multidimensional nature of HRQOL
- limited psychometric data to support reliability and validity, and the absence of a clear conceptual framework (Thompson, 2009).

### RATIONALE FOR DEVELOPMENT OF TBI CARE-QOL

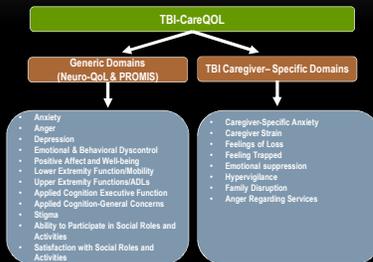
- We need VALID and RELIABLE measures in order to develop appropriate interventions for these care partners and determine if our treatments are effective.
- We need BRIEF measures to minimize response burden for participants.



## DEVELOPMENT AND VALIDATION OF NEW COMPUTER ADAPTIVE TESTS

- **Stage 1**
  - Qualitative study to identify the most important aspects of HRQOL for a given population
- **Stage 2**
  - Quantitative study to field test the newly developed items
    - (n = 500-600 participants)
- **Stage 3**
  - Quantitative validity study

### STAGE 1: QUALITATIVE STUDY (18 FOCUS GROUPS)



### CIVILIAN VS. SMV CARE PARTNERS

- There is substantial overlap among the different care partner groups with regard to HRQOL.
  - Both groups talked about anxiety, but care partners of SMVs included much more hypervigilance.
  - Care partners of SMVs placed greater emphasis on emotional suppression.
- Both groups expressed anger, but SMV groups had a different flavor.

**BN1** Update with Figure used in TBi-CareQOL Validations?

Boileau, Nicholas, 8/6/2019

## CAREGIVER-SPECIFIC ANXIETY

- Includes feelings of worry and anxiety specific to general safety, health, and future well-being of the person with the injury
  - "I'm here now. I'm here now but part of me is still at home because part of me is still worried about my son"
  - "You're scared for them, because they don't know how to decipher good from bad anymore"
  - "I still worry about it, especially with the depression and everything. I'm just afraid he'll get pushed to that limit"
  - "As a caregiver, one of the things that I get concerned about is – for my son in particular, is what's going to happen to him"
  - "How do I protect him if I am gone?"

## CAREGIVER STRAIN

- Includes feelings of being overwhelmed, stressed, self-defeated, down-trodden, and beat-down related to the caregiver role
  - "You know, and I feel as if nothing I can do is right"
  - "So sometimes that's how I just feel, like just want to give up"
  - "I don't feel sufficient you know dealing with him"
  - "And then you get to this point where you don't want to think about anymore because the situation just seems impossible"
  - "sometimes I feel like throwing up my hands and just saying, 'go back to your mom.'"
  - "I'm going to die of stress."
  - "And there's no end to it. You can't say, well, he'll be better next month"

## FEELINGS OF LOSS

- Includes feelings of sorrow, mental suffering or distress over changes related to the TBI. This includes changes and feelings of loss about the person with the TBI or themselves or others that are affected by the injury
  - "So I feel like my life has kind of fallen through the cracks"
  - "and it was – it's like, okay, my world is just ending, and there's nothing I can do about it"
  - "What makes it worse is that you're constantly remembering the person they used to be"
  - "there's a lot of loneliness, because you lose your husband"
  - "It's our new life. Life – my life will never be the same, never. It's changed forever"
  - "but there's no amount of counseling that's going to help the fact that the person that you know is gone"
  - "And to see him the way he is now, it's like – it breaks your heart"

## FEELING TRAPPED

- Includes feelings that you are unable to go places or do things due to caregiving responsibilities
  - "And so I feel very trapped, because he's my responsibility"
  - "it's like you're tied to the house or wherever they are"
  - "there's this little thing in the back of your brain saying, you know he's not there, and you've got to go home and make sure"
  - "It's very hard to go out and leave them alone"

## EMOTIONAL SUPPRESSION

- Hiding or suppressing negative feelings while acting in the caregiver role (e.g., protecting others or maintaining functioning).
  - "How do you feel?" That's a question I get a lot. "How do you feel?" I try not to."
  - "Just suppressing all of the emotions and all of that to where you go to bed with a headache because all day you just wanted to scream and cry, but you couldn't because then they get upset."
  - "I don't even get to express like bad work days, or bad days, because he doesn't understand why I'm mad or what's going on..."
  - "You don't show your soldier that you're upset"

## HYPERVIGILANCE

- Feelings of anxiety, hyperarousal, and/or vigilance related to concerns about the emotional and behavioral status of the person with the TBI.
  - "Because you walk around on eggshells"
  - "But how it affects me is I have to be – I think sensitive, really, really sensitive, to the things that may trigger – may trigger her"
  - "So your entire days is tailored around, okay, if we encounter this situation, how do I pull him out of it and get the kids this way"
  - "So it's like we're constantly on guard to make sure that people around them don't create an atmosphere that's going to trigger a negative response from them"

## FAMILY DISRUPTION

- Feelings that caring for the person with TBI has disrupted family life
  - "I feel the person I care for's injury has disrupted my family life."
  - "I feel the person I care for's injury has changed the relationships in my family."
  - "I feel my family life revolves around the care the person I care for needs."

## FRUSTRATION WITH MILITARY HEALTH CARE SERVICES

- Feelings of irritability, anger, frustration reactivity, and resentment related to barriers to physical and mental health services (for both caregivers and service members).

## BARRIERS FOR SMVS CARE

- Emphasis on an inability to obtain services, as well as problems with available services
  - "He's still fighting to get his TBI documented."
  - "We waited about six months to try to get him an appointment 'cause he was having problems breathing."
  - "it's not always possible to drive a three hour round trip or a 6 ½ or 7 ½ hour round trip whenever you're suffering"
  - "I think it would be really nice if we actually could know what the services are.. It's like a scavenger hunt..."
  - "We have so many doctors, and they don't communicate."

## BARRIERS FOR CARE PARTNERS

- Emphasis on lack of services, lack of respect/recognition, and monetary compensation
  - "there's a lot of things...for the vets, but not necessarily...directed to the vets and the caregiver"
  - "I feel like I get totally ignored"
  - "I've applied for Caregiver three times and been denied"
  - "I've given up my life as a civilian to take care of a soldier defending this nation, and I deserve the same respect and equality that a spouse would have."

## The TBI-CareQOL Study:

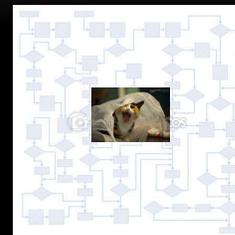
DEVELOPMENT OF NEW COMPUTER ADAPTIVE TESTS FOR CAREGIVER STRAIN, CAREGIVER-SPECIFIC ANXIETY, FEELINGS OF LOSS, FEELING TRAPPED, EMOTIONAL SUPPRESSION, CAREGIVER VIGILANCE AND FRUSTRATION WITH MILITARY HEALTH CARE SERVICES



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September 2019



## COMPUTER ADAPTIVE TESTING (CAT)



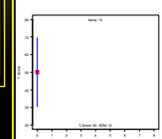
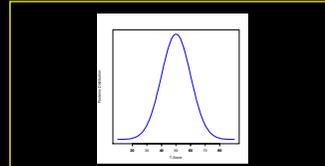
# ITEM BANK

- Domain = Emotional Functioning
- Subdomain = Depression
- Item Bank (50 items)
- In the past 7 days...
  - I felt sad.
  - I felt depressed.
  - I felt like a failure.
  - I felt worthless.
  - I felt that nothing could cheer me up.
  - [and so on...]

- 1 = Never
- 2 = Rarely
- 3 = Sometimes
- 4 = Often
- 5 = Always

I felt sad:  
 1. Never  
 2. Rarely  
 3. Sometimes  
 4. Often  
 5. Always

T-Score = 50 SE = 10

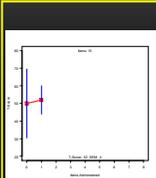
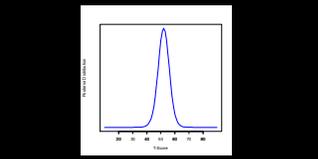


Next Best Item:  
I felt depressed

I felt depressed

- 1. Never
- 2. Rarely
- 3. Sometimes
- 4. Often
- 5. Always

T-Score = 52 SE = 4

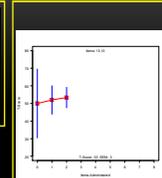
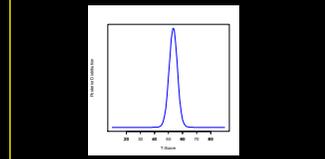


Next Best Item:  
I felt like a failure

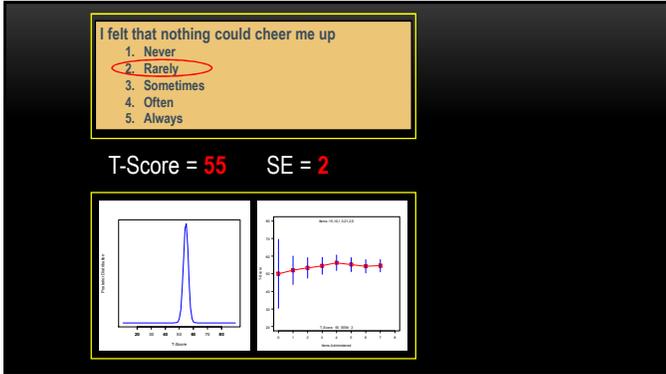
I felt like a failure

- 1. Never
- 2. Rarely
- 3. Sometimes
- 4. Often
- 5. Always

T-Score = 53 SE = 3



...



- ### PRO DEVELOPMENT PROCESS ACCORDING TO ESTABLISHED PROMIS STANDARDS
- Stage 1:
    - Qualitative study to identify the most important aspects of HRQOL for a given population
  - Stage 2:
    - Quantitative study to field test the newly developed items (n = 500-600 participants)
  - Stage 3:
    - Quantitative validity study

- ### PARTICIPANT DEMOGRAPHICS
- N = 560 Caregivers (344 civilian- & 216 military-)
  - 85.4% Female
  - Average age = 47.4 years (SD=14.6)
  - 76% Caucasian; 14% African American
  - 10.5% Hispanic
  - 58.3% Spouses; 23.0% Parents; 7.7% Other family members
  - Average time in caregiver role = 5.9 years (SD = 5.1; range 0 to 59)

### ITEM DEVELOPMENT

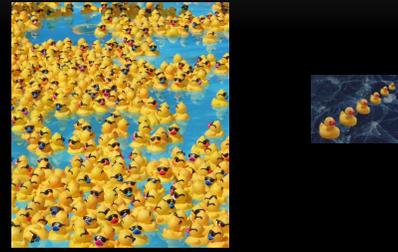
Domain	Item Pool	Expert Review	Expert Review	Cognitive Interviews	Translation review	Literacy review	Consensus Meeting	Final Items
Caregiver Strain	75 Items	(-16 + 8) 67 Items	(-13 + 28) 82 Items	(-6 1R) 76 Items	(-10 39R) 66 Items	(NC) 66 Items	(2R) 66 Items	66 Items
Caregiver-Specific Anxiety	75 Items	(-20 + 36) 72 Items	(-18 + 25) 82 Items	(+ 18) 100 Items	(-10, 50R) 81 Items	(NC) 81 Items	(8R) 81 Items	81 Items
Feeling Trapped	75 Items	(-50) 25 Items	(-1 + 9) 33 Items	(-5 1R) 28 Items	(15R) 28 Items	(NC) 28 Items	(NC) 28 Items	28 Items
Feelings of Loss	75 Items	(-14 + 11) 72 Items	(-1 + 60) 131 Items	(-4 14R) 127 Items	(-29 75R) 98 Items	(NC) 98 Items	(2R) 98 Items	98 Items

ITEM DEVELOPMENT



Domain	Item Pool	Expert Review	Cognitive Interviews	Translation review	Literacy review	Consensus Meeting	Final Items
Caregiver Suppression	43 Items	(-8 -9) 46 Items	(-3 9R) 43 Items	(1R) 43 Items	(NIC) 43 Items	(NIC) 43 Items	43 Items
Caregiver Vigilance	41 Items	(-16 +8) 33 Items	(2R) 33 Items	(-1) 32 Items	(NIC) 32 Items	(NIC) 32 Items	32 Items
Family Disruption	6 Items	(-3 -1) 4 Items	(NIC) 4 Items	(NIC) 4 Items	(NIC) 4 Items	(NIC) 4 Items	4 Items
Caregiver Frustration with Services	51 Items	(-20 +19) 80 Items	(-8 10R) 72 Items	(-3 9R) 69 Items	(-5 1R) 64 Items	(NIC) 64 Items	64 Items

STAGE 2: FROM AN ITEM POOL TO AN ITEM BANK



FROM AN ITEM POOL TO ITEM BANK



Domain	Item Pool	EFA E1/E2 Ratio >4	1-factor CFA loading <.5	1-factor CFA resid corr >.20	1-factor CFA MD>100	Item-adjusted total score corr <.4	Sparse cells (n<10)	Problems with monotonicity	IRT item misfit	DIF	Final item bank
Caregiver Strain	66 Items	✓	0 Items	3 Items	9 Items	1 Item	13 Items	0 Items	7 Items	0 Items	33 Items
Caregiver-Specific Anxiety	81 Items	✓	2 Items	22 Items	18 Items	0 Items	8 Items	0 Items	4 Items	0 Items	27 Items
Feeling Trapped	28 Items	✓	0 Items	1 Item	10 Items	0 Items	1 Item	0 Items	1 Item	0 Items	15 Items
Feelings of Loss - Self	71 Items	✓	0 Items	18 Items	9 Items	1 Item	0 Items	0 Items	13 Items	0 Items	30 Items
Feelings of Loss - Person w TBI	27 Items	✓	0 Items	0 Items	1 Item	0 Items	0 Items	0 Items	7 Items	0 Items	19 Items

FROM AN ITEM POOL TO ITEM BANK



Domain	Item Pool	EFA E1/E2 Ratio >4	1-factor CFA loading <.5	1-factor CFA resid corr >.20	1-factor CFA MD=100	Item-adjusted total score corr <.4	Sparse cells (n<10)	Problems with monotonicity	IRT item misfit	DIF	Final item bank
Emotional Suppression	43 Items	✓	1 Item	6 Items	10 Items	1 Item	0 Items	0 Items	4 Items	0 Items	21 Items
Vigilance	32 Items	✓	0 Items	7 Items	5 Items	0 Items	0 Items	0 Items	2 Items	0 Items	18 Items
Family Disruption	4 Items	✓	0 Items	0 Items	0 Items	0 Items	0 Items	0 Items	1 Item	N/A	3 Items
Frustration with Military Health Care	64 Items	✓	0 Items	4 Items	1 Item	0 Items	1 Item	0 Items	15 Items	0 Items	42 Items

BN3

**BN3** The Technical name for this is "Health Care Frustration"

Boileau, Nicholas, 8/6/2019



### EMOTIONAL SUPPRESSION (6-ITEM SHORT FORM)



1. I hide my emotions from people I am close to.
2. If I feel angry, I keep it to myself.
3. I hide my anger from the people I love.
4. I keep a smile on my face so others will not know something is wrong.
5. I isolate myself emotionally.
6. I pretend to be happy when I am around most people.

### CAREGIVER VIGILANCE (6-ITEM SHORT FORM)



1. I have to monitor my environment to avoid triggers for the person I care for.
2. I spend time controlling the environment for the person I care for.
3. I try to control other people's behavior in order to avoid triggers for the person I care for.
4. I serve as a buffer between the person I care for and other people.
5. I avoid situations that are likely to cause the person I care for to have an outburst.
6. I spend time trying to make sure I do not anger the person I care for.

### FAMILY DISRUPTION (3-ITEM SHORT FORM)



1. I feel the person I care for's injury has ruined my family life.
2. I feel the person I care for's injury has disrupted my family life.
3. I feel my family life revolves around the care the person I care for needs.

### FRUSTRATION WITH MILITARY HEALTH CARE SERVICES (CAREGIVER SPECIFIC 6-ITEM SHORT FORM)



1. I am frustrated with how long it takes for the military to provide services for caregivers.
2. I am frustrated with barriers to accessing services for caregivers.
3. I am angry that I have to find information about caregiver services on my own.
4. I am angry that the military does not address my needs as a caregiver.
5. I am angry with the military due to the lack of support for caregivers.
6. I am bothered by the lack of services for caregivers.

## FRUSTRATION WITH MILITARY HEALTH CARE SERVICES (PERSON WITH TBI SPECIFIC 6-ITEM SHORT FORM)



1. I am frustrated with the lack of communication with my service member's health care team.
2. I am bothered with how long my service member has to wait to obtain services.
3. I am angry with the way my service member is treated by his/her treatment team.
4. I am frustrated with how difficult it is to access care for my service member.
5. I am frustrated with the lack of services available for my service member.
6. I am angry about the lack of care coordination for my service member.

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