



# Traumatic Brain Injury Caregiver Quality of Life Study Newsletter

www.med.umich.edu/CODA/TBI-CareQOL

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## What is TBI-CareQOL?

The Center for Clinical Outcomes Development & Application (CODA) at the University of Michigan (UM) is conducting a research study, TBI-CareQOL, to investigate health-related quality of life of caregivers of individuals with traumatic brain injury (TBI). The five-year study is funded by the National Institute of Nursing Research (part of the National Institutes of Health), and involves 4 collaborating sites: Kessler Foundation in New Jersey, The Institute for Rehabilitation and Research Memorial Hermann in Texas, Walter Reed National Military Medical Center in Maryland, and Northwestern University in Illinois. Both civilian and military caregivers are included in this study.

The purpose of the TBI-CareQOL study is to develop a questionnaire to measure quality of life of caregivers of individuals with TBI. Caregivers of individuals with TBI have been identified as an underserved population, and research has shown that improving quality of life of caregivers improves outcomes of the people that they provide care for. Ultimately the questionnaire developed in this study will allow researchers and clinicians to better assess caregiver quality of life and will be used to develop more appropriate interventions for caregivers, leading to improved quality of life for caregivers and the individuals they care for.

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## Meet the Principal Investigator of TBI-CareQOL



### Noelle E. Carozzi, Ph.D.

*Assistant Professor, Physical Medicine & Rehabilitation*

*Director, Center for Clinical Outcomes Development & Application (CODA)*

Dr. Noelle E. Carozzi is an Assistant Professor in the Department of Physical Medicine & Rehabilitation (PM&R) at the University of Michigan. In 2013, she

founded the Center for Clinical Outcomes Development & Application (CODA). Partnering with fellow Assistant Professor of PM&R, Dr. Anna Kratz, CODA has established a reputation for groundbreaking research, developing sensitive measures to detect and improve quality of life for individuals suffering from chronic illness, as well as their families.

Dr. Carozzi is currently principal investigator of two large, multi-site National Institutes of Health-funded grants. These include the TBI-CareQOL study and the HDQLIFE study, which aims to develop a questionnaire to measure quality of life of people with Huntington Disease. She is also a co-investigator on several smaller studies investigating quality of life in other conditions including neonatal brachial plexus palsy, mild cognitive impairment, traumatic brain injury, spinal cord injury, stroke, and multiple sclerosis.

Dr. Carozzi is a licensed clinical psychologist with expertise in clinical neuropsychology and research methods. Her work with individuals with TBI began in 2007. Through her work with individuals with TBI and their families, she became aware of the challenges that they face and the impact that these challenges have on the quality of life of the entire family. She observed that medicine in the setting of a severe brain injury is wholly centered on the patient and often fails to acknowledge the need to provide care and support to the caregivers. She recognized that the process of rehabilitation is challenging for the entire family and that "lots of the pieces of the puzzle were being ignored". The TBI-CareQOL study is designed to address this gap by developing a tool to evaluate caregiver quality of life, leading to improved interventions for caregivers.

*"For the often overlooked population of caregivers, providing a forum and tools for giving them a voice is a step toward better quality of life both for them and their loved one."*

-Noelle E. Carozzi, Ph.D.

We asked Dr. Carozzi to describe her experience after moderating caregiver focus groups. She replied, "I was struck by how caregivers are hesitant to speak about themselves, but they readily comment about the person for whom they provide care." In a patient centered medical climate, TBI-CareQOL empowers caregivers with a voice to address their own needs.

## Cheryl Gansner

*Program Coordinator, Hearts of Valor*

*CODA had the opportunity to speak with Cheryl Gansner, the wife of a severely injured veteran. Cheryl graduated with her Bachelor of Social Work Degree and began working as a program coordinator with Hearts of Valor in August of 2010, where she plans retreats, writes for the newsletter, and provides peer support.*



**UM:** *What led you to provide support to military caregivers?*

**CG:** I was first working with children in social work. After Bryan was injured in 2006, I started doing some contract work with Vocational Rehabilitation for the VA at Walter Reed. There I was able to connect with other warriors and their caregivers and it shifted my interest from working with children to working with wounded warrior families.

One night while at Walter Reed I couldn't sleep so I started googling support for caregivers of wounded warriors and I found Wounded Warrior Wives through Operation Homefront. I jumped on the forums and started chatting with other caregivers that were going through the same challenges as I was. A few years after I was offered a job working with the program as they had read my blog and knew that I liked advocating for others.

Wounded Warrior Wives changed to Hearts of Valor and Sara [Boz], the director, and myself have been expanding the program since then. It is an honor to serve caregivers of wounded, ill or injured veterans and service members post-9/11. I have walked in their shoes and we came out as a stronger couple after his injury, and it has made me want to help others.

**UM:** *What challenges do you believe are unique to caregivers of veterans who have sustained a TBI?*

**CG:** Caregivers of veterans who served in Iraq and Afghanistan are unique because they will be caregiving for decades. Typically caregivers are faced with shorter amounts of time because they are caring for end-of-life illness or diseases [whereas TBI requires a long term commitment]. This causes caregiver burnout more quickly and it is much more expensive for the VA to provide decades of care for these wounded warriors. TBIs present interesting challenges because no two TBIs look the same; therefore, there isn't a one-size-fits-all protocol.

Securing appropriate medical care can be hard. There are long

wait times, there is lag time between the military and VA, and compensation can be deferred from months to years. Navigating through the red tape is challenging and truly the caregivers are the best advocates for the veterans. It is a long, exhausting process in which the whole family unit needs to be supported.

**UM:** *HOV generously offers annual retreats for caregivers. How do you witness the caregivers transforming throughout their time together?*

**CG:** We are an education-based retreat. The caregivers come home with more tools in their toolbox. They are able to navigate the VA more easily, know the risks for caregiver burnout, build friendships so that they go home with a support team, and have connections to other organizations that can help them on this journey.

**UM:** *Are there particular resources that you would recommend for caregivers?*

**CG:** This is currently my favorite one stop shop for caregiver resources; <http://www.moaa.org/caregiver/>.

**UM:** *If you could send 3 professionals to a caregiver's home to provide support, who/what services would you imagine are most needed?*

**CG:** *Respite:* that way the caregiver can get a much-needed break. The VA provides respite care for the injured veteran, but they can't watch the children, so a respite care worker can provide care for both the warrior and children so that the caregiver can truly get a few hours away.

*Handyman services:* a lot of warriors can no longer work in the yard. Mowing services, mulching and weeding are much needed. Also, small repairs around the house are needed and sometimes impossible for the warrior to complete.

*Counseling:* co-pays rack up easily for mental health services; some caregivers don't have health insurance or the non-profits that provide therapy for free aren't offered in their city. Having a safe place to vent is much needed and can prevent caregiver burnout.

**UM:** *Is there one piece of advice or a message that you would like to offer caregivers?*

**CG:** Don't try to be superman/superwoman. It is impossible! Reach out, ask for help and build a support network for yourself. 'The strongest people are not those that show strength in front of us but those who win battles that we know nothing about.' These caregivers are winning battles that the majority of the population knows nothing about.

**UM:** *What do you witness during the course of a support group for caregivers?*

**CG:** When I see the caregivers hanging out outside of the group I know that they are building a support network and friendships that they need to carry them through. It is amazing to see them relate and share their struggles and not compare them. When the sessions go on for hours I know that they are doing good work and enjoy being around those that get what they have been through.

**UM:** *Is there anything else you'd care to relay as a spokesperson for caregivers?*

**CG:** Please take the time to read through the RAND study on Hidden Heroes. This was the first study done of its kind and is very important. [http://www.rand.org/pubs/research\\_reports/RR499.html](http://www.rand.org/pubs/research_reports/RR499.html).

## Our Journey to Recovery

July 26, 2006 is a day our family will never forget. The vivid details of that day will be in our memory as long as we live. Shock, confusion, disbelief are some of the words that describe our reaction to "the call." Our son, Jason, had been in a car accident, hit head-on by a semi-truck. The moment we received "the call" we never could have imagined the journey we would be taking.

As we look back at the road of recovery, vivid images become so real. Seeing Jason for the first time, the attending nurse trying to explain what we saw as we entered the room, crying and praying out to God that our son would live. As family and friends gathered, the all-night vigil began.

Jason's injuries were very serious; brain trauma, internal injuries that required emergency surgery, broken neck, severe damage to the entire left side of his body and every day the doctors discovered so many other problems. During Jason's hospital stay of almost two months, we remember a nurse from the trauma unit saying, "We perform miracles here" and it was true. We were on an emotional roller coaster, never knowing what we would have to face each day. Yes, we endured daily obstacles that we never dreamed we could get through. We were much stronger than we ever thought we could be.

The thought of bringing Jason home was very frightening. We became the caregivers, on duty every hour of every day. Exhausted, the days were tense as we helped our son, never giving up. Wheelchairs, special beds, walkers, braces, bandages, medicines, IVs, doctor's appointments, lawyers, insurance companies, were all a part of our life now. With family, friends and compassionate home nurses, Jason became "our miracle."

We look back now and realize this tragedy was filled with so many blessings. We are different people now and we've learned so much about the human spirit. We feel we can now help others. We are hoping that by sharing a small part of our experience, others will know that they too will get through those life-changing events.

On a positive note, Jason is doing very well. He is enrolled in college hoping to be a social worker and he has an internship in the hospital where his life was saved. He is married to a wonderful woman and they are expecting their first child. Coincidence? We don't see it that way. Jason's wounds are healed but the scars are still visible as a reminder that life can be taken away at any moment.

Forever grateful,

*Jim and Kay*

P.S. Don't forget to take care of yourself, if only for a few minutes. It is so important. There are so many angels among us, don't be afraid to ask for help and also graciously accept any help that is offered.



*A caregiver in action*

## CODA Research Registry

The purpose of the registry is to keep the names and contact information of people who are interested in participating in future research studies at CODA at the University of Michigan. Enrolling in the registry will allow us to contact you if you might be eligible to participate in a new research study that we are conducting.

If you join the CODA registry, we will collect basic information from you, such as your birth date, race, gender, and contact infor-

mation, as well as your medical diagnosis, if applicable. This information will be used to see if you are a good fit for a future study.

By joining this registry, you will have the opportunity to participate in studies that you may not otherwise learn about.

To learn more about being on the CODA registry, please contact the CODA study team at 734-764-0644 or via email at [PMR-CODALab@med.umich.edu](mailto:PMR-CODALab@med.umich.edu).

If you have questions or want to learn more about the TBI-CareQOL study, please contact CODA:

**Phone** 734-764-0644

**Email** [TBIcaregiver@med.umich.edu](mailto:TBIcaregiver@med.umich.edu)

**Web** [med.umich.edu/CODA/TBI-CareQOL](http://med.umich.edu/CODA/TBI-CareQOL)

## Recruitment Update

The TBI-CareQOL study is beginning its 3rd year this summer! We have nearly completed the focus group and interview portion of the study. Thank you to our more than 100 participants who have participated in the study with our study personnel from University of Michigan (MI), Kessler Foundation (NJ), The Institute for Rehabilitation and Research Memorial Hermann (TX), and Walter Reed National Military Medical Center (MD). The sites are shown on the map below.



We have two phases remaining in the study:

**Phase 1:** Participants will complete a two-hour long computer-based survey. Participants will answer several questions about their health-related quality of life, demographic questions, and questions about the person they care for. Participants can complete this session at their home or at the study site, and they will receive \$50 for completion of this session. All sites are currently recruiting participants for this phase of the study, which will begin in summer 2014.

**Phase 2:** Participants will complete a two-hour long computer-based survey. Participants will answer several questions about their health-related quality of

life, demographic questions, and questions about the person they care for. Participants will take the same survey two times (within two weeks of one another). Participants can complete these sessions at home or at the study site, and will receive \$60 for completion of the first session and \$70 for completion of the second session. Recruitment for this portion of the study is expected to begin in spring 2016.

**The next phase of our study will begin in *Summer of 2014*.**

**Those who have participated in earlier phases of the study will be contacted.**

**If you wish to enroll, please email [PMR-TBIcaregiver@med.umich.edu](mailto:PMR-TBIcaregiver@med.umich.edu) or call CODA at 734-764-0644**



TBI-CareQOL is a research study conducted by the University of Michigan Medical School, sponsored by the National Institute of Health (NIH) and in partnership with PROMIS<sup>®</sup>

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