Epidemiology of Brain Injury as a Chronic Condition: Evidence from the TBI Model Systems National Database

Angelle M. Sander, Ph.D., FACRM

Professor, H. Ben Taub Department of PM&R

Baylor College of Medicine

Director, Brain Injury Research Center

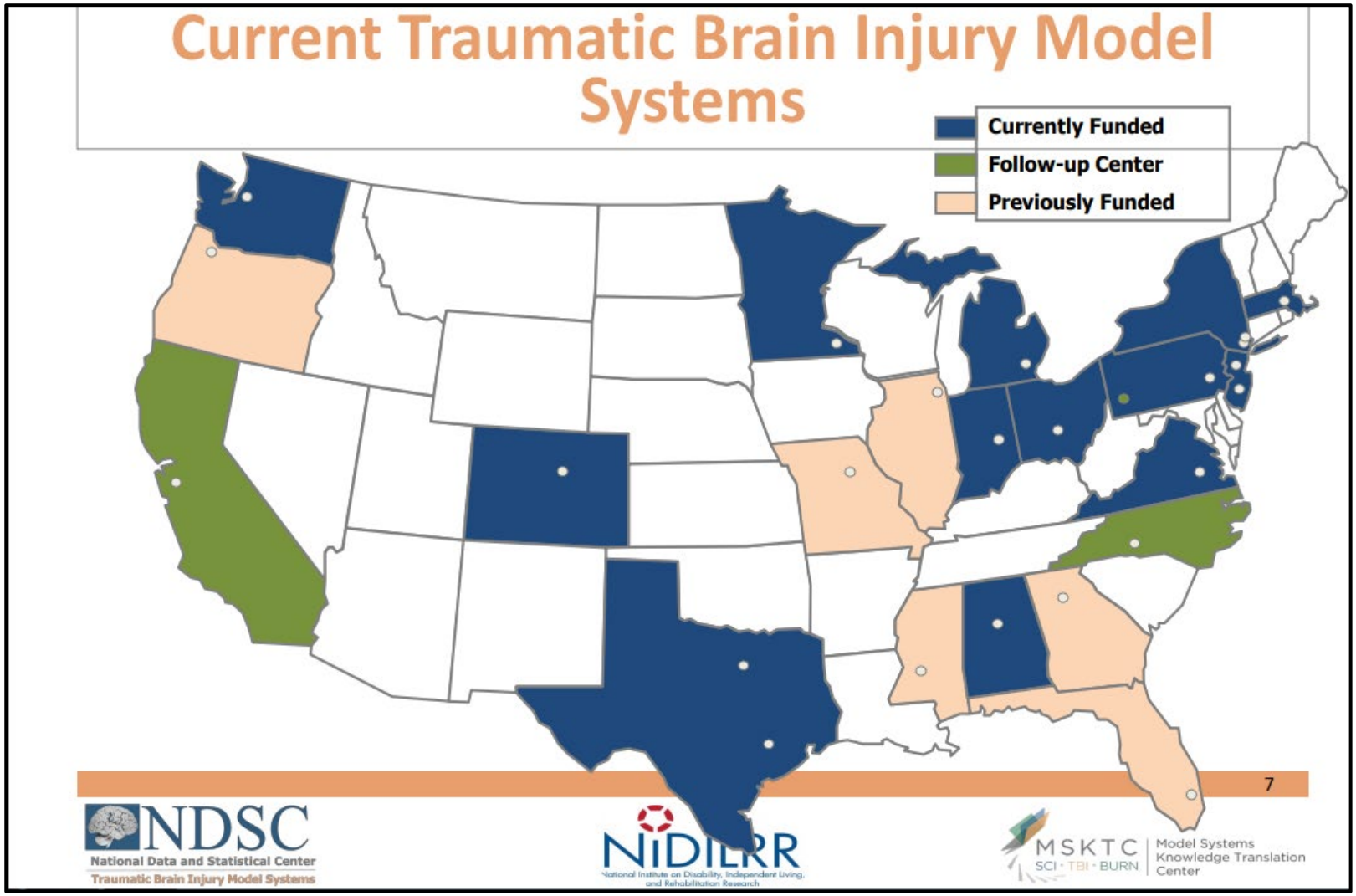
TIRR Memorial Hermann

angelle.sander@memorialhermann.org

Baylor College of Medicine

H. BEN TAUB DEPARTMENT OF PHYSICAL MEDICINE & REHABILITATION

TIRR MEMORIAL HERMANN Rehabilitation & Research


Current Traumatic Brain Injury Model Systems
Currently Funded
Follow-up Center
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NDSC
National Data and Statistical Center
Traumatic Brain Injury Model Systems
NIDILRR
National Institute on Disability, Independent Living, and Rehabilitation Research
MSKTC
SCI · TBI · BURN
Model Systems Knowledge Translation Center

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Traumatic brain injury as a chronic disease: insights from the United States Traumatic Brain Injury Model Systems Research Program

Kristen Dams-O'Connor, Shannon B Juengst, Jennifer Bogner, Nancy D Chiaravalloti, John D Corrigan, Joseph T Giacino, Cynthia L Harrison-Felix, Jeanne M Hoffman, Jessica M Ketchum, Anthony H Lequerica, Jennifer H Marwitz, A Cate Miller, Risa Nakase-Richardson, Amanda R Rabinowitz, Angelle M Sander, Ross Zafonte, Flora M Hammond

Traumatic brain injury (TBI) is a global health priority, associated with substantial burden. Historically conceptualised as an injury event with finite recovery, TBI is now recognised as a chronic condition that can affect multiple domains of health and function, some of which might deteriorate over time. Many people who have had a TBI remain moderately to severely disabled at 5 years, are rehospitalised up to 10 years post-injury, and have a reduced lifespan relative to the general population. Understanding TBI as a chronic disease process can be highly informative for optimising care, which has traditionally focused on acute care. Chronic brain injury care models must be informed by a holistic understanding of long-term outcomes and the factors that can affect how care needs evolve over time. The United States Traumatic Brain Injury Model Systems of Care follows up individuals with moderate-to-severe TBI for over 30 years, allowing characterisation of the chronic (2–30 years or more post injury) functional, cognitive, behavioural, and social sequelae experienced by individuals who have had a moderate-to-severe TBI and the implications for their health and quality of life. Older age, social determinants of health, and lower acute functional status are associated with post-recovery deterioration, while younger age and greater functional independence are associated with risky health behaviours, including substance misuse and re-injury. Systematically collected data on long-term outcomes across multiple domains of health and function are needed worldwide to inform the development of models for chronic disease management, including the proactive surveillance of commonly experienced health and functional challenges.

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Brain Injury Research Center, Department of Rehabilitation and Human Performance, Brain Injury Research Center (Prof Kristen Dams-O'Connor PhD) and Department of Neurology (Prof Kristen Dams-O'Connor), Icahn School of Medicine at Mount Sinai, New York, NY, USA; Brain Injury Research Center, TIRR Memorial Hermann, Houston, TX, USA (S B Juengst PhD, Prof A M Sander PhD);

Key Points

- Even with completion of specialized brain injury rehabilitation, individuals with TBI have chronic problems in one or more domains of outcome, at intervals ranging from 2 to 30 years after injury.[1]
- Functional outcomes are dynamic, rather than static, with many individuals who experience improved or stable functioning experience decline at a subsequent period. Change is more common than stability.[1]
  - A subset of the people who survive show improvement in functioning up to 10 years post-injury, with the most improvement seen early after injury.[1]
  - Physical functioning improves and plateaus earlier, with cognitive functioning continuing to improve up to 5 years post-injury.[1]
  - More than half of individuals who survived were moderately to severely disabled at 5 years after injury,[2] with decline common from 5 to 10 years post-injury.[3]
  - Decline in the first 5 years was associated with poorer overall health at time of injury and psychiatric comorbidities.[4,5]
  - Decline from 5 to 10 years was associated with medical comorbidities.[4,5]
  - Most people who were not able to follow commands at rehab admission were independent in self-care and activities of daily living by 10 years.[6,7]

Key Points

- Changes in cognition over time is an under-researched area and requires further attention.
- High rehospitalization rates
- Risk for subsequent TBI
- Common co-morbid health conditions
- Risk for mood disorders and suicide
- Participation across employment, social relationships, and community activities, remains low across first 5 years.
- Life satisfaction- 36-41% more dissatisfied than not, with stability over first 5 years
- Problem substance use
  - 17% problem alcohol use at 5 years post-injury; 12% illicit drug use
  - Initial decline in use followed by increase

Key Points

- Outcome in different domains are related and interactive, but also distinct, and one outcome cannot be taken as indicative of outcomes in other areas. Treating one domain alone may not be effective for improving outcomes in another domain.[1]
- Risk for chronic poor outcomes is greater for certain subgroups of participants, including older age, race or ethnicity other than White, and those with disability earlier post-injury. Younger patients with greater functional independence and pre- or post-injury problem substance use are at risk for higher risk behaviors, re-injury, and early mortality.[1]
- Risk for chronic poor outcomes is also impacted by individual differences in co-morbid health conditions, lifestyle fitness, access to care, and physical and social environment.[1]

Risk factors for poor outcomes in chronic traumatic brain injury by domain in the TBIMS

Function

Functional disability

- Older age[17,18]
- Longer time to follow commands or heightened severity of acute disability[18–24]
- Comorbidities[25,26]
- Protective factors: better overall health[26] and socioeconomic advantage after injury (eg, availability of state support for brain injury services, insurance status and type, and income)[18,19,24,27]

Cognition

- Insufficient evidence in the Traumatic Brain Injury Model Systems of Care (TBIMS) for demographics, injury severity, or acute cognition[28]

Risk factors for poor outcomes in chronic traumatic brain injury by domain in the TBIMS

Participation

Low community participation

- Persistent fatigue[47]
- Depression[48]
- Neighbourhood characteristics (eg, neighbourhood unemployment rate, racial and ethnic background of residents, educational attainment of residents, household composition, and age of housing structures)[49]
- Protective factors: White race, cohabitation, higher education, or higher cognitive function;[48] caregiver and family functioning (level of caregiver distress and the caregiver's perceived social support);[50] and availability of state-level TBI services[27]

Relationships (marital stability)

- Protective factors: female sex, older age, non-violent injury, or no substance misuse;[51,52] greater global disability (in racial or ethnic minority groups only)[51]

Unemployment

- Racial or ethnic minority group[49,53–60]
- Depression[61]
- Protective factors: younger age at injury;[42,53–55,60] higher education;[60,55–57] male sex or married;[60] employed preinjury;[53,55–57,60] less severe injury;[42,56,57] non-violent cause;[55] craniotomy (*vs* craniectomy);[62] and greater functional independence[60]

Reduced driving

- Seizures or injury severity[63]
- Black (*vs* White) race[63]
- Protective factors: employment or family income[63]

Dissatisfaction with life

- Middle age (45–64 years)[32]
- Black race[64]
- Psychiatric or other health conditions[25,65]
- Protective factors: older adulthood (age >65 years);[66] and community participation or functional independence[38,67,68]

Risk factors for poor outcomes in chronic traumatic brain injury by domain in the TBIMS

Physical and behavioural health

Comorbidities

- Seizures: Black individuals are at three-times higher risk than White individuals[29,30]

Sleep and fatigue

- Poor sleep hygiene or depression[31]

Mood

- Depression: middle age (30–50 years) at time of injury or Black race (*vs* White)[32,33]
- Chronic psychiatric symptoms: post-traumatic epilepsy,[30] unemployment, low income,[33] anxiety or depression symptoms 1 year post injury[34,35]
- Functional impairment or participation restrictions[35,36]
- Increasing suicidal ideation: severe injury, younger age, or Black race[37]
- Protective factors: depression: Hispanic (*vs* White);[35] participation in religious services;[38] and resilience or stress coping ability (as measured by the Connor-Davidson Resilience Scale) 3 or 6 months after injury[39]

Substance use

- Preinjury substance misuse[40,41]
- Employment status[42]
- Younger age[32,40]
- Male sex[42]
- Lifetime history of two or more traumatic brain injuries (TBIs)[43]

Re-injury

- Substance misuse or younger age[43,45]

Mortality

- Older age, male sex, education ceased before high school, unemployed at injury, fall-related TBI, not discharged home, less functional independence, or difficulty walking and feeding[46]

Key Points

- Evidence highlights the need for a bio-psychosocial-ecological approach to management of TBI as a chronic condition.[1,8]

- We know far less about chronic outcomes for individuals who sustain moderate to severe TBI and do not receive inpatient rehabilitation, or about those who may not receive even Level One trauma care. Fewer than 15% of individuals with moderate to severe TBI in the U.S. receive inpatient rehabilitation. Outcomes may also be different for those who do or do not receive a variety of outpatient post-acute rehabilitation services. Systematic community-based studies of individuals with different levels of care are needed.

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