

MAY 0 4 2021

The Honorable Patrick J. Leahy Chairman Committee on Appropriations United States Senate Washington, DC 20510

Dear Mr. Chairman:

The Department's response to section 721 of the John Warner National Defense Authorization Act for Fiscal Year 2007 (Public Law 109–364) is enclosed. Section 721 requires a longitudinal study on the effects of Traumatic Brain Injury (TBI) incurred by members of the Armed Forces serving in Operation IRAQI FREEDOM or Operation ENDURING FREEDOM with a report after the third, seventh, eleventh, and fifteenth years of this study.

This 11-Year Update report summarizes significant findings regarding TBI outcome complexities, and provides 7 conclusions with 25 data-driven areas of emphasis to enhance existing support for Service members, veterans, their families, and providers. TBI recovery varies across Service members and veterans, highlighting the importance of identifying factors early that might complicate recovery, such as mental health problems, chronic pain, and sleep disturbances or disorders. Co-occurring physical and mental health problems are widespread following TBI and link to poor outcomes, underscoring the need for multi-disciplinary care. Further, the report reveals that those with chronic TBI may experience barriers to care due to disability or lack of family support. The report conveys that family education and support are critical components of acute inpatient rehabilitation. TBI-related difficulties affect the family more broadly than the immediate caregiver. Caregiving families experience health problems frequently, while TBI caregivers report poor mental health and lower quality of life. Therefore, assessment of the family unit as a whole may be necessary to achieve optimal outcomes.

Thank you for your continued strong support for our Service members, veterans, and families. I am sending similar letters to the President of the Senate, the Speaker of the House, and the other congressional defense committees.

Sincerely,

Unginia S. Penrod

Virginia S. Penrod Acting

Enclosure: As stated

cc: The Honorable Richard C. Shelby Vice Chairman



MAY 0 4 2021

The Honorable Rosa L. DeLauro Chairwoman Committee on Appropriations U.S. House of Representatives Washington, DC 20515

Dear Madam Chairwoman:

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Sincerely,

Unginia S. Penroe

Virginia S. Penrod Acting

Enclosure: As stated

cc: The Honorable Kay Granger Ranking Member



MAY 0 4 2021

The Honorable Jack Reed Chairman Committee on Armed Services United States Senate Washington, DC 20510

Dear Mr. Chairman:

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Sincerely,

Virginia S. Penrod

Virginia S. Penrod Acting

Enclosure: As stated

cc: The Honorable James M. Inhofe Ranking Member



MAY 0 4 2021

The Honorable Adam Smith Chairman Committee on Armed Services U.S. House of Representatives Washington, DC 20515

Dear Mr. Chairman:

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Sincerely,

Vuginia S. Penrod

Virginia S. Penrod Acting

Enclosure: As stated

cc: The Honorable Mike D. Rogers Ranking Member



MAY 0 4 2021

The Honorable Kamala D. Harris President of the Senate United States Senate Washington, DC 20510

Dear Madam President:

The Department's response to section 721 of the John Warner National Defense Authorization Act for Fiscal Year 2007 (Public Law 109–364) is enclosed. Section 721 requires a longitudinal study on the effects of Traumatic Brain Injury (TBI) incurred by members of the Armed Forces serving in Operation IRAQI FREEDOM or Operation ENDURING FREEDOM with a report after the third, seventh, eleventh, and fifteenth years of this study.

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Sincerely,

Unginia S. Penrod

Virginia S. Penrod Acting

Enclosure: As stated



READINESS

MAY 0 4 2021

The Honorable Nancy Pelosi Speaker of the House U.S. House of Representatives H-209, The Capitol Washington, DC 20515

Dear Madam Speaker:

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Sincerely,

Unginia S. Penrod

Virginia S. Penrod Acting

Enclosure: As stated

Report to Congress



Eleven-Year Update: Longitudinal Study on Traumatic Brain Injury Incurred by Members of the Armed Forces in Operation IRAQI FREEDOM and Operation ENDURING FREEDOM

May 2021

In response to: Section 721 of the John Warner National Defense Authorization Act for Fiscal Year 2007 (Public Law 109–364)

> The estimated cost of this report or study for the Department of Defense (DoD) is approximately \$24,000.00 in Fiscal Years 2020–2021. This includes \$0.00 in expenses and \$24,000.00 in DoD labor.

> > Generated on 2020Nov10

RefID: D-1F58499

INTRODUCTION

This report is in response to section 721 of the John Warner National Defense Authorization Act (NDAA) for Fiscal Year (FY) 2007 (Public Law 109–364), which requires that the Secretary of Defense "conduct a longitudinal study on the effects of traumatic brain injury [TBI] incurred by members of the Armed Forces serving in [Operation IRAQI FREEDOM (OIF) or Operation ENDURING FREEDOM (OEF)] on the members who incur such an injury and their families." Congress directed that the study run for 15 years, and that the Department submit reports after the third, seventh, eleventh, and fifteenth years in consultation with the Secretary of Veterans Affairs. In 2009, the Secretary of Defense directed the Traumatic Brain Injury Center of Excellence (TBICOE)/Defense and Veterans Brain Injury Center, a component of the Defense Health Agency (DHA) Research and Development Directorate, to address this congressional mandate.

In compliance with the Secretary of Defense's direction, the Department of Defense (DoD) supports two component studies. The first, the 15-Year Studies, consists of three sub-studies: (1) the Natural History of TBI Study; (2) the Caregiver and Family Member Study (Longitudinal Caregiver Study and TBI Caregiver Quality of Life Development Study); and (3) the Archival Studies. Each sub-study targets specific subsets of Service members, veterans, and their families. In 2015, the DoD launched the second component study, Improved Understanding of Medical and Psychological Needs in Veterans and Service Members with Chronic TBI (IMAP). IMAP supplements the infrastructure and leverages the Department of Veterans Affairs (VA) TBI Model Systems Program lifetime study to examine the rehabilitation and health care needs of Service members and veterans with TBI.

The 3-Year Update, submitted to Congress on June 18, 2013, described the methodology for the 15-Year Studies. The 7-Year Update summarized 7 years of the 15-Year Studies and 2 years of IMAP data, with 6 conclusions and 9 recommendations provided to Congress on July 19, 2017. To identify relevant, impactful, and actionable findings for inclusion in the 11-Year Update, study investigators presented key findings to a group of TBI clinicians, subject matter and policy experts, patients, caregivers, and hospital administrators to gather feedback during a series of meetings held between December 2019 and August 2020. This 11-Year Update includes cumulative findings that contribute to the body of knowledge on the complexities of TBI outcomes, and offers seven conclusions with 25 data-driven areas of emphasis within existing capabilities that serve Service members, veterans, families, and the providers charged with their care. This 11-Year Update was developed in consultation with the VA.

BACKGROUND

DoD defines a TBI as a traumatically induced structural injury or physiologic disruption of brain function as a result of an external force, with accompanying alteration of mental status, loss of memory for events immediately before or after the injury, or a loss of consciousness of any length. Most TBI is mild in severity, and most individuals who sustain a mild TBI (mTBI or concussion) will undergo full recovery. However, those with a moderate, severe, or penetrating TBI, multiple mTBIs, or co-occurring medical or mental health conditions, experience varied and sometimes prolonged recoveries.

Dissemination and Translation Activities

To date, study investigators published 187 peer-reviewed manuscripts, 265 abstracts, and 7 special journal issues using data from the 15-Year Studies and IMAP (see Appendix A for cited manuscripts and abstracts). They have also given 417 conference presentations. As of this 11-Year Update, the studies increased the representativeness of the sample by including more moderate-severe and acute TBI cases, post-injury data points, and robust measurement tools, particularly in areas of emerging importance such as medical comorbidities and sleep disorders.

This longitudinal research aligns with ongoing DoD and VA efforts. Evidence from the 7-Year Update has informed TBI and brain health-relevant mandates and programming. Since the last report, efforts have centered on improved clinical monitoring to address medical, mental health, and rehabilitation needs, including suicide prevention, following TBI.

YEAR 11 STUDY OUTCOMES

Section 721 of the NDAA for FY 2007 (Public Law 109–364) requires that the longitudinal study of TBI address four elements informing study design, data collection, and data analysis for the 15-Year Studies. Although the sample used to generate this report does not fully represent the entirety of possible TBI outcomes for the military or veteran population as a whole, it does represent a diversity of injury characteristics and individuals in need of ongoing support. Data from this sample inform the report's conclusions and recommendations, which intend to identify gaps in knowledge that will support this population. Although many conclusions for TBI apply across all severities, this report also specifies those unique for specific TBI severities. The following sections present research findings relevant to each element.

Element 1: The Long-Term Physical and Mental Health Effects of TBIs Incurred by Members of the Armed Forces during Service in Operation IRAQI FREEDOM or Operation ENDURING FREEDOM

Recovery from TBI is Varied; Many Service Members Report Good Outcomes while Others Do Poorly

- For most Service members, mTBI does not represent a long-term health issue and typically results in better outcomes than for those with a more severe TBI.^{1,2}
- For some Service members with mTBI, a number of factors can complicate recovery. These include psychological factors, level of resilience, and sleep quality.³⁻⁹
- Co-occurring posttraumatic stress disorder (PTSD) is the most potent factor identified for risk of long-term symptoms.⁴⁻⁷

- Low psychological resilience, more common among those with chronic mTBI symptoms, strongly influences neurobehavioral outcomes, such as anxiety, depression, or stress.^{5,8,9}
- Participants who report more blast exposure also report more distress, post-concussive symptoms (e.g., headache, fatigue), and worse quality of life.^{10,11} A potential relationship exists between blast effect and a heightened emotional response to a threat or other factor.^{10,11} This blast effect may be independent of the presence or absence of TBI.¹⁰
- Symptoms do not follow a straight trajectory. Symptom reports often fluctuate over time; some may worsen, improve, or newly emerge. Data do not demonstrate definitively that TBI directly results in late symptom onset, warranting consideration of other factors.⁷

<u>Co-Occurring Physical Health Problems are Common after TBI and are Associated with Poor</u> <u>Outcomes Highlighting the Need for Multi-disciplinary Care</u>

- Injured Service members and veterans experience increased rates of physical health problems compared to those without any injury history. Those with a history of TBI incur the greatest health risk, almost half of which report at least three problems.¹²⁻¹⁵
- Common problems associated with TBI include chronic pain (e.g., back pain, headache), sleep disturbance and disorders, orthopedic injuries, cardiovascular disease (e.g., hypertension, high cholesterol), sexual dysfunction, and gastrointestinal disease.¹²⁻¹⁵
- Service members and veterans experiencing these problems after TBI have worse recovery and outcomes across multiple domains, to include general distress, functional cognition, physical independence, need for supervision and/or caregiver support, mental health, social engagement, employment, and satisfaction with life.¹²⁻¹⁵
- Sleep disturbances are common after TBI and are reported at a higher rate after mTBI.³ Objective measures suggest that sleep apnea is more common with more severe TBI.¹⁶⁻¹⁸ Regardless of injury type or severity, sleep disturbances are associated with greater symptom complaints and worse neurobehavioral outcomes (e.g., anxiety, anger, depression, functioning, and stress).^{3,5,19-21}

<u>Co-Occurring Mental Health Problems are Common after TBI and are Associated with Poor</u> <u>Outcomes Including Reduced Social Engagement, Legal Problems, and Family Distress</u>

- Service members and veterans with TBI and those injured without TBI experience poorer long-term mental health compared to peers without injury.²²
- The presence of mental health symptoms, especially posttraumatic stress symptoms, is the most important factor related to long-term outcomes.^{4,23,24}
- The presence of PTSD with alcohol/illicit drug use is a significant risk factor for lower community engagement and higher risk of arrest after TBI.²⁵

- These problems are compounded when combined with poor psychological resilience.^{5,9}
- While men and women both report symptoms following mTBI, symptom expression may be different, with the greatest differences among those with concurrent PTSD.²⁶⁻²⁸
- Service members and veterans with PTSD and co-occurring depression, anger, irritability, and aggression are more likely to have a negative impact on family cohesion.^{29,30}

<u>Cognitive Health Problems are Common, Especially after Severe and Penetrating TBI, Resulting in Greater Care Needs</u>

- Objective and subjective tests reveal that poor cognitive health is common after TBI. Objective testing reveals greater impairment among those with severe and penetrating TBI.³¹
- As a result, those with severe and penetrating TBI require extensive support and supervision by a caregiver for safety.³² For those with mTBI who report or experience cognitive problems, other physical or mental health problems are significant contributing factors.³³
- Cognitive problems, such as memory deficits or problem-solving difficulties, persist years following the TBI event with variable recovery trajectories. Physical and mental health factors may contribute to this variability.^{31,33}

As part of ongoing 15-Year study efforts, the DoD conducted advanced neuroimaging studies on many enrolled study participants. Additionally, the DoD stored blood samples for analyses of genetic and proteomic markers of clinical states and associated outcomes. While the neuroimaging and blood-based biomarker data have yielded interesting findings to date, it is too soon to draw general conclusions from this information. Since the state of the science rapidly evolves, it is best to view these data types in the context of findings from other published data and research teams. This report does not present this type of analysis, as it is beyond its scope.

Element 2: The Health Care, Mental Health Care, and Rehabilitation Needs of Such Members for Such Injuries after the Completion of Inpatient Treatment through the DoD, the VA, or Both

<u>Rehabilitation Needs across Physical and Mental Health Care, Service Coordination, Community</u> <u>Re-entry, and Self-Care are Common after Inpatient Treatment and Suggest Importance of</u> <u>Innovative Long-Term Care Models</u>

• Hospital readmission, predominantly for rehabilitation, is common during the first year following moderate to severe TBI, particularly among those with more severe injuries or those who sustained their injuries during deployment.³⁴

- Service members and veterans who received inpatient TBI rehabilitation continue to have rehabilitation needs for at least five years after TBI. On average, they report eight ongoing rehabilitation needs and three needs unmet by current care. Frequently cited areas of ongoing need include cognitive health (e.g., help with memory, problem solving), managing physical symptoms, and mental health (e.g., stress, emotional disturbances). Service coordination of physical and mental health needs is also critical.^{35–37}
- Nearly half of those surveyed report social needs 5 years after TBI, including help with engaging in recreational/social activities and finding opportunities to socialize with others.^{35–38}
- Five years after TBI, up to one-third report having informational needs and needing assistance in the home, finding employment, getting around the community, and transitioning to civilian life.³⁷
- Ongoing unmet rehabilitation needs lowered participation in social and community activities and increased levels of depression, resulting in overall lower satisfaction with life.³⁶

Family Education and Support are Critical Components of Acute Inpatient Rehabilitation; however, Needs are Common during Chronic Stages of TBI Suggesting Need for Ongoing Services

- For those receiving inpatient treatment for TBI, the most commonly met family needs were in the areas of receiving health information, staff respect for patient/family wishes, and explanations in understandable, straightforward terms.³⁹
- The most common unmet needs reported by family members of those in the chronic stages of TBI were helping others understand the changes of their loved one with TBI, insufficient respite from caregiving duties, and opportunity to discuss their feelings with someone who has gone through a similar experience.³⁹⁻⁴¹

Environmental Barriers, Healthcare Inequities, and Co-Occurring Mental Health Problems are Associated with Unmet Rehabilitation Needs

- Service members, veterans, and families report environmental barriers, such as distance to healthcare, time issues, and scheduling/availability of wanted services, as challenges to address ongoing needs.⁴¹
- Among Service members and veterans with the most rehabilitation needs, over half report experiencing primary barriers, including community access to care limitations, availability of wanted or needed information, and attitudes of the family members or caregivers providing support.⁴¹

- Approximately one-third of the study sample report experiencing limitations in the availability of healthcare, in-home assistance, and public transportation options.⁴¹
- Minority status is a significant risk factor for unmet rehabilitation needs. Black Service members and veterans report having greater unmet needs for help with managing emotions (52 percent), improving health (44 percent), community reintegration and employment (20–36 percent), and independence in the home (28 percent).³⁵
- Families of Service members or veterans with TBI and co-occurring mental health problems are more likely to have unmet needs. During the first 5 years following a TBI, families report between three and eight unmet needs when the Service member or veteran has co-occurring mental health problems, compared to two unmet needs reported by families of Service members or veterans without a mental health problem.⁴¹

Element 3: The Type and Availability of Long-Term Care Rehabilitation Programs and Services Within and Outside the DoD and the VA for Such Members for Such Injuries, Including Community-Based Programs and Services and In-Home Programs and Services

Rehabilitation Programs are Available across the VA, DoD, and the Community

• The Military Health System (MHS) and the Veterans Health Administration (VHA) collaborate with community-based organizations to implement programs that support treatment, rehabilitation, and long-term care of Service members and veterans with TBI. These programs also support transition from the MHS to the VHA and into home- and community-based programs.

Facilitators and Barriers to Care Access Exist in Chronic Stages of TBI

- Factors that help Service members and veterans access needed care include: ongoing engagement with rehabilitation staff in the years post-TBI, engaged family members who serve as advocates, flexibility to use private sector healthcare resources in addition to VA/DoD treatment facilities, proximity to care, knowledge of existing services, and service availability.⁴²
- Barriers to accessing needed care for Service members and veterans include: physical distance from desired services, poor communication between providers, administrative issues (e.g., challenges with scheduling systems, wait times), stigma, availability of services, and transportation to appointments.⁴²
- Service utilization is different across TBI severity, which may result from cognitive, physical, or access barriers. Despite high rates of service utilization, those with mTBI are more likely to access mental health care (more than three-quarters sampled), whereas those with moderate-severe TBI less frequently use such services. Studies note this disparity across physical health conditions, as well.^{43,44}

Element 4: The Effect on Family Members of a Member Incurring TBI

Caregiving Needs are Common Years after TBI and Caregivers Assist with a Variety of Needs

- TBI severity and comorbid conditions influence the care intensity and role of the family caregiver. On average, family caregivers have been in their caregiving role for more than seven years, with a significant portion providing more than 10 hours of care daily.⁴⁵⁻⁴⁹
- The caregiving role varies considerably, ranging from emotional support to assistance with activities of daily living. Family caregivers most frequently provide assistance with cognitive support, stress management, relationship maintenance, service coordination, and supportive care. Management of behavioral difficulties is frequent and includes assisting with symptoms of anxiety, posttraumatic stress, irritability, and aggression.^{40,45–47,50}

Caregivers Experience High Rates of Burden, Poor Mental Health, and Lower Quality of Life Attributed to TBI and Non-TBI Factors

- Co-occurring physical health problems (e.g., pain, headache), psychological distress (e.g., anxiety, depression, and verbal or physical expressions of irritability/anger/aggression), and PTSD in the Service member or veteran is associated with higher rates of caregiver burden and worse quality of life.^{45,46,48-51}
- Caregivers experiencing high levels of caregiving burden are more likely to report having less time for themselves, a greater caregiving time commitment, financial burden from out-of-pocket expenses related to their caregiving duties, negative impact on their work, and financial burden from lost income due to their caregiving responsibilities.^{46,48}
- Caregivers who experience these added burdens experience poor mental health. Poor caregiver mental health is associated with stress in their caregiving relationship with the Service member or veteran and lower confidence in their caregiving skills.^{45,46,49,52}
- The Service member's or veteran's functional ability relating to mood, interpersonal interactions, and insight is more predictive of family distress than his/her functional ability relating to sensory, motor, and cognitive functioning.³⁰
- Caregivers of Service members and veterans with TBI and more severe PTSD experience worse caregiver health-related quality of life outcomes, greater family disruption, and more strain and anxiety in the caregiver role.⁴⁰

<u>Health Problems are Common among Caregivers and Children of Service Members and Veterans</u> with TBI

• Family caregivers frequently report headaches, gastrointestinal issues, obesity, hypertension, and sleep problems.⁴⁰

- Children of Service members and veterans with TBI report a number of frequently cooccurring medical problems, such as attention-deficit/hyperactivity disorder, learning disorders, asthma, allergies, autism, gastrointestinal and motor disorders, depression, and cognitive disorders.⁴⁰
- Children in families where the Service member or veteran shows evidence of anger, anxiety, and depression, have significant behavioral health problems.⁴⁰

Providing Accurate Assessment of Caregiver Health, Needs, and Service Accessibility is Important for Health-Related Quality of Life

- This research expanded the National Institutes of Health-supported TBI Quality of Life Measures to develop a new measurement system, the Traumatic Brain Injury Caregiver Quality of Life (TBICareQOL), which evaluates both general and caregiving-specific aspects of health-related quality of life among TBI caregivers. Subscales unique to the military caregiving experience examine potential frustrations with the military health care system, access to services, and caregiver hypervigilance when faced with their loved one's expressions of anger, irritability, and explosiveness. This level of vigilance is more common among military caregivers than civilian ones.^{53–55}
- Caregivers who are also military beneficiaries have certain privileges for which a nonbeneficiary does not automatically qualify, such as base access to military medical treatment facilities, military health care, and on-base conveniences. Caregivers who are non-military beneficiaries (e.g., parents, siblings, unrelated caregivers) may face unique challenges in their caregiving role that negatively impact health-related quality of life.⁵¹

CONCLUSIONS AND WAY FORWARD

The MHS and VHA are committed to bettering TBI patient care through thoughtful translation of relevant research findings into practice. Reports such as this 11-Year Update increase visibility on evidence-based findings relevant to Service members, veterans, families, TBI care providers, and policy experts to ultimately update and optimize standard of care. TBICOE works closely with the DHA TBI Advisory Committee and engages the Deputy Assistant Director of Medical Affairs to disseminate updated findings to relevant clinical care communities. The DoD has established internal and external partnerships to include the National Intrepid Center of Excellence (NICOE) and the Intrepid Spirit Center Network; Uniformed Services University of the Health Sciences; VA; National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) within the Department of Health and Human Services; as well as academia and non-profit groups. The DoD keeps these partners apprised of relevant findings with regular dialogue on how to incorporate research into a particular system of care.

Within DoD, section 721 research findings have: (1) raised attention to depression, sleep, and PTSD with increased screening for these conditions in the care of these patients; (2) provided empirical data in support of the need for multi-disciplinary care settings to treat TBI; (3) increased focus on caregiver and family needs to include their health and well-being, such as

the translation of findings from this report into an active revision of the congressionallymandated Family Caregiver Guide, and improved caregiver health-related quality of life assessment through the TBICareQOL; (4) supported working groups on clinical recommendations (CR), such as a newly revised sleep CR; and (5) promoted continued evaluation of the most impactful components of TBI care through efforts such as the TBICoE Outcomes activity, and research such as the joint DoD-VA Optimizing Rehabilitation InterventiONs study for Cognition Following Complex TBI.

In response to the section 721 research findings, the VA: (1) continues to screen all veterans from OEF/OIF for possible mTBI during their initial visit to the VHA to enhance identification and treatment of TBI and any related physical, cognitive, and emotional problems; (2) convened a summit with NICoE partners to determine consensus on treatment delivery, outcome metrics, and programmatic structure for Polytrauma intensive TBI and PTSD programs; (3) reviewed access and capacity of Polytrauma intensive TBI and PTSD programming across the Polytrauma System of Care, and recommended further increasing its capacity; (4) increased access to comorbid TBI and PTSD evaluation and care through expanded clinical video telehealth capabilities and enhanced care coordination for transitioning Service members and long-term follow up; (4) established a new partnership between the VA Quality Enhancement Research Initiative and the Physical Medicine and Rehabilitation National Programs dedicated to knowledge translation and rapid implementation of research findings into coordinated and standardized clinical practice across VA Polytrauma Centers; and (5) awarded four new TBIfocused grants to test the feasibility of a sleep apnea treatment adherence protocol, examine a brief aggression treatment for veterans with comorbid PTSD, conduct a secondary analysis of IMAP data to identify alternative chronic pain treatment to opioid use, and participate in the multisite chronic TBI BeHEALTHY NIDILRR-funded Disability and Rehabilitation Research Project.

Element 1: The Long-Term Physical and Mental Health Effects of TBIs Incurred by Members of the Armed Forces during Service in Operation IRAQI FREEDOM or Operation ENDURING FREEDOM

Conclusion 1: Recovery from TBI is varied; many Service members and veterans report good outcomes, while others do poorly, highlighting the need for assessment and identification of factors related to outcomes.

1. Assessment and identification of those factors that might complicate recovery, such as mental health problems, chronic pain, and sleep disturbances/disorders, should be addressed early through the health care system.

Conclusion 2: Co-occurring physical and mental health problems are common after TBI and are associated with poor outcomes, which emphasize the need for multi-disciplinary care.

2. A need exists for integrated, multi-disciplinary care to address physical, psychological, and cognitive health after TBI, especially co-morbidities associated with worse recovery (e.g., PTSD, low resilience, sleep disorders, chronic pain). Providers should be aware of these comorbidities to screen and manage as clinically indicated.

- 3. Coordinated care should begin early after TBI onset and continue during the transitions of care that occur as the Service member or veteran lives and ages with TBI during its chronic stages.
- 4. Evaluation of patients with late onset, persistent, or refractory symptoms and TBI-related needs should include screening and management, as appropriate, for common physical and mental health comorbidities, particularly posttraumatic stress symptoms and PTSD.
- 5. Future working groups engaged with clinical practice guidelines should review and consider assessment of mental health, cognitive, sleep, and pain conditions for those who demonstrate delayed recovery and persistent symptoms.

Conclusion 3: Cognitive health problems are common, especially after severe and penetrating TBI, highlighting the greater associated care needs in this group.

- 6. It is important to educate clinicians around the variable recovery trajectory, particularly following severe TBI.
- 7. Those with cognitive problems may have an impaired ability to participate or engage in their care; therefore, a need exists to identify and address obstacles and barriers specific to this population.
- 8. VA and DoD clinical teams should continue to address comorbid health conditions that contribute to poor cognition and less effective cognitive rehabilitation.

Element 2: The Health Care, Mental Health Care, and Rehabilitation Needs of Such Members for Such Injuries after the Completion of Inpatient Treatment through the DoD, the VA, or Both

Conclusion 4: Rehabilitation needs across physical and mental health care, service coordination, community re-entry, and self-care are common after inpatient treatment, emphasizing the importance of innovative long-term care models that address unmet rehabilitation needs.

- 9. Models of care should continue to address health literacy and self-advocacy, and utilize self-management techniques (when applicable) to maximize compliance with evidence-based treatments.
- 10. Models of care and future directions should continue to address any healthcare disparities that may exist across racial and disability (physical, cognitive, and mental health) groups.
- 11. Innovative models of care that destigmatize delivery and receipt of mental health care are important areas of emphasis.

Conclusion 5: Family education and support are critical components of acute inpatient rehabilitation; however, needs are common in chronic stages of TBI, highlighting the importance of ongoing services through chronic stages of TBI.

- 12. Access to support and educational services generally available during the acute stages of recovery wanes across the patient's lifespan; therefore, it will be important to explore coordinated and enduring engagement for patients and families for those with severe and chronic functional impairment.
- 13. Programs addressing TBI and mental health needs of Service members and veterans should also continue to address family needs across many domains, including health informational support, involvement in care, access to appropriate community support networks, as well as professional, emotional, and instrumental support in accordance with agency legislative authorities.

Element 3: The Type and Availability of Long-Term Care Rehabilitation Programs and Services Within and Outside the DoD and the VA for Such Members for Such Injuries, Including Community-Based Programs and Services and In-Home Programs and Services

Conclusion 6: Rehabilitation programs are available across the VA, DoD, and the community. Facilitators and barriers to care access exist in the chronic stages of TBI and are associated with rehabilitation and family needs. Items 14–19 provide a framework for understanding future directions related to care access.

- 14. Service members and veterans experience physical, psychological, and cognitive problems that may impair their ability to recognize, participate in, or access care to address their needs; therefore, care programs should continue to adapt as needed to increase accessibility for disabled Service members and veterans who lack assistance or family support.
- 15. Mental health services for anxiety, depression, and substance misuse should continue to accommodate persons with cognitive and physical impairments.
- 16. Future directions should continue to support TBI care across the continuum of recovery, including aging with TBI.
- 17. Future directions should consider limited access to programs in the MHS for non-military beneficiaries who serve in a caregiving capacity.
- 18. Future directions and programs should continue to address environmental barriers to receiving care for needs, such as distance to healthcare, time issues, and scheduling / availability of wanted services; and maximize known facilitators to care access, including knowledge of existing services in DoD, VA, and the community, and availability to utilize them.

19. Care programs that continue to destigmatize and increase access to mental health services may increase acceptance of mental health treatment.

Element 4: The Effect on Family Members of a Member Incurring TBI

Conclusion 7: Caregivers of persons with TBI experience high rates of burden, poor mental health, and lower quality of life. Health problems are common in caregiving families and should be adequately assessed.

Items 20-23 are specific to caregivers of Service members with TBI.

- 20. TBI-related difficulties affect the family more broadly than the immediate caregiver; therefore, assessment of the family unit as a whole may be necessary to achieve maximal success. Since long-term services for Service members with persistent care needs do not typically include services for dependent children, it is important to address the physical and emotional health needs of these individuals.
- 21. Assessment of family needs should include use of evaluations designed for this population that address the domains of need typically endorsed by families.
- 22. Care settings may best address ongoing caregiver/family needs that are co-located with those that provide services for the Service members in accordance with agency authorities for the provision of care.
- 23. Non-military beneficiaries who adopt the caregiving role (e.g., parents and siblings) need similar access to resources and services across the MHS care continuum as caregivers who are beneficiaries.

Items 24-25 highlight caregivers of veterans with TBI.

- 24. Individualized Rehabilitation and Community Reintegration Plans of Care for veterans with TBI and comorbid conditions should address caregiver needs that support the caregivers and support the veterans' successful community reintegration (e.g., health information and training, involvement in care, access to appropriate community support, and engagement with the VA Caregiver Program).
- 25. Long-term care coordination models should address changing caregiving needs across the lifespan, including caregivers' knowledge of and access to available VA and community long-term services and support for veterans with TBI, their caregivers, and families.

Summary

In response to section 721 of the John Warner NDAA for FY 2007 (Public Law 109–364), this 11-Year Update report summarizes significant findings regarding TBI outcome complexities, and provides seven conclusions with 25 data-driven areas of emphasis within existing support for Service members, veterans, their families, and providers. TBI recovery varies across Service

members and veterans, highlighting the importance of identifying factors early that might complicate recovery, such as mental health problems, chronic pain, and sleep disturbances or disorders. Co-occurring physical and mental health problems are widespread following TBI and link to poor outcomes, underscoring the need for multi-disciplinary care. Further, the report reveals that those with chronic TBI may experience barriers to care due to disability or lack of family support. The report conveys that family education and support are critical components of acute inpatient rehabilitation. However, caregiving families experience health problems frequently, while TBI caregivers report poor mental health and lower quality of life. TBI-related difficulties affect the family more broadly than the immediate caregiver; therefore, assessment of the family unit as a whole may be necessary to achieve optimal outcomes.

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