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A Latent Content Analysis of Barriers and Supports to Healthcare: Perspectives From Caregivers of Service Members and Veterans With Military-Related Traumatic Brain Injury

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Abstract

Objective: To identify barriers and supports that caregivers of individuals with military-related traumatic brain injury (TBI) encounter when navigating the military healthcare system; this information will be used as the foundation of a new patient-reported outcome measure.

Setting: Community.

Participants: Forty-five caregivers of service members and veterans (SMV) who sustained a medically documented mild, moderate, severe, or penetrating TBI.

Design: Latent content analysis.

Main Measures: Nine focus group discussions of barriers and supports to navigating the military healthcare system and community resources.

Results: Latent content analysis indicated that caregivers discussed barriers (66%) and supports (34%) to obtaining care within the military healthcare system and the community. Caregivers most frequently discussed SMVs' interactions with healthcare, their own interactions with healthcare, family care, and community organizations.

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Conclusions: Caregivers confront numerous challenges while pursuing healthcare services. Although much of the discussion focused on barriers and perceived unmet needs within the military healthcare system, caregivers also recognized supports within the military healthcare system and general community. Increased attention to accessibility and quality of services, as well as reducing financial burden, can lead to improved health-related quality of life for caregivers and their SMVs.

Keywords

caregiver; health-related quality of life; outcome assessment (healthcare); quality of life; service members; traumatic brain injury; underserved populations; veterans; wounded warriors

MORE THAN 357 000 military service members have been diagnosed with traumatic brain injury (TBI) since 2000.¹ While the majority of TBIs sustained by service members are typically mild in severity and do not result in poor long-term outcomes, such injuries are often associated with an increased risk of posttraumatic stress disorder, chronic pain, and headaches.^{2,3} For those service members with moderate, severe,⁴ or penetrating⁵ TBIs, persistent and sometimes devastating deficits are more common, including physical problems,^{6–9} cognitive decline,^{10–16} and emotional/mental health problems.^{17–20} These problems can lead to changes in the family system, as family members assume the role of “caregiver” and bear primary responsibility for assisting the person with TBI with physical, mental, financial, and leisure activities.²¹ Regardless of TBI severity, concomitant mental health and physical injuries are common (ie, polytrauma).^{22,23} Not surprisingly, such problems can be associated with unhealthy family functioning,²⁴ as well as negative outcomes for both the caregiver^{24,25} and the person with the TBI.^{25–32}

Given the large number of US service members and veterans (SMVs) with TBI,¹ as well as the long-term sequelae and healthcare needs of these individuals^{2,33–37} and their families,^{38,39} maximizing treatment outcomes and functioning is essential. Many TBI survivors require both formal and informal care, often in the form of family member caregivers. The Department of Defense (DoD) and Veterans Affairs (VA) Health Care Systems have developed significant care systems around TBI. These include specialized TBI programs with dedicated providers (including neurologists, neuropsychologists, physiatrists, psychiatrists, and rehabilitation providers). In addition to these systems, case management networks are in place to track patients through the care continuum. In the DoD, care for more severe TBI initially takes place largely in the National Capitol region or in San Antonio. In the VA Health Care System, care for more severe TBI is centered in the polytrauma care system. Milder TBI is typically treated proximal to the patients’ unit or family, except in the case of a few specialized programs. Details of this care continuum are given elsewhere.^{40–44} Typically, individuals initially receive care in the DoD care system. Following separation from the military, they transition to the VA system. In some circumstances, individuals may access care in either system if the services that they need are not available in their primary care system. Unfortunately, the complexity of the military healthcare system can present a challenge to accessing needed services.

While providing high-quality care for SMVs is a national priority, a number of potential barriers to care have been identified. Specifically, access to care (including long wait times, geographic distance, and difficulties scheduling appointments)^{45–47} and perceived stigma about receiving healthcare services (especially when concomitant mental health issues are present)^{48–53} have been highlighted as significant barriers to high-quality care. In addition, unmet family/spousal needs^{54–58} and a general lack of knowledge about where to get services^{55,57,58} are common complaints within the military healthcare system. Thus, there is a need to better understand the challenges that these individuals and their families encounter within the military healthcare system. Therefore, the purpose of this study was to conduct focus groups with caregivers of SMVs who have sustained a TBI during their military service in an effort to identify barriers and supports experienced when navigating the military healthcare system to provide the foundation for the development of a new patient-reported outcome measure that can capture caregiver concerns in this area. This is the first report, to our knowledge, that directly evaluates SMV caregivers' perceptions of the military healthcare system.

METHODS

Participants

Participants included 45 caregivers of SMVs who sustained a mild, moderate, severe, or penetrating TBI (see Table 1 for detailed demographic information). Care-givers were recruited from around the nation through hospital-based recruitment and community outreach programs at both Walter Reed National Military Medical Center (Bethesda, Maryland) and the University of Michigan (Ann Arbor, Michigan). Hearts of Valor, a community organization that supports caregivers of wounded warriors, also served as a means for recruitment. Participants were included if they were at least 18 years of age, able to read and understand English, and caring for an SMV with a medically documented TBI that was 1 year or more postinjury. TBI diagnosis was confirmed through medical record documentation of a mild, moderate, severe, and/or penetrating TBI (according to DoD criteria⁵). Comorbid bodily injuries were not used as an exclusion criterion. A response of 1 or more on the following screening question was used to confirm caregiver role: “On a scale of 0–10, where 0 is ‘no assistance’ and 10 is ‘assistance with all activities,’ how much assistance does the person you care for require from you to complete activities of daily living due to problems resulting from his/her TBI? Activities could consist of personal hygiene, dressing and undressing, housework, taking medications, managing money, running errands, shopping for groceries or clothing, transportation, meal preparation and cleanup, remembering things, etc.”

Prior to participation in the study, informed consent was obtained from all participants. All data were collected in agreement with local institutional review boards.

Data collection and analysis

Nine in-person focus groups (between November 2013 and June 2014) were conducted to identify the most relevant and significant barriers and supports that caregivers encountered when navigating the military healthcare system. These groups were part of a larger study

that examined overall health-related quality of life⁵⁹ for these SMV caregivers (details regarding broader research questions are highlighted elsewhere⁶⁰). A focus group methodology was selected because it meets established standards for measurement development⁶¹ (a broader goal of the larger study), as well as its participatory action emphasis^{62,63} and its overall efficiency (in terms of data collection).⁶⁴

On average 5 individuals participated in each 90-minute focus group (range 2–8 individuals per group); groups were not separated = by caregiver type or gender. Groups were moderated by 1 or 2 PhD-level clinical psychologists (N.E.C. or A.L.K.) with extensive experience and training in this methodology; an additional observer was present to take notes. In accordance with written informed consent, focus groups were audio-recorded, transcribed verbatim, and deidentified. Specific questions were included about access to care (see Appendix 1); these questions were the primary focus of the current analysis.

NVIVO 10 software (QSR International, Cambridge, Massachusetts) was used to conduct the frequency analysis according to established methodology.⁶⁵ Briefly, a deductive approach where the text is assigned to predetermined codes that are theoretically- or empirically based was used to develop the overall codebook.^{66–68} This iterative process involved the investigator team (9 members with PhDs, 2 members with MAs, and 1 member with a BS). Specifically, the PhD-level focus group moderators (N.C. and A.K.) and an additional study team member (T.B.) independently drafted initial code-books; these were then merged into a single document after discussion (ie, triangulation). This codebook was then reviewed and edited independently by all team members. Comments were reviewed by the study principal investigator (N.E.C.) and merged into a single document, which was then finalized during a teleconference meeting with all team members (see Appendix 2).

Following the codebook development, a latent content analysis approach was used to analyze the text (which utilizes frequency counts to summarize the transcript text).^{69–71} First, interrater reliability (greater than or equal to 80% agreement) was established between the 2 experienced raters (1 BS level and 1 PhD-level psychologist served as the rater for this analysis). Then, using the newly developed codebook, the raters individually coded each of the 9 transcripts; the raters were required to reach a consensus through discussion for any identified discrepancies. Percentages represent the number of times each concept was discussed relative to the total number of concepts discussed within the codebook; summary counts reflect total number of concepts both within and across participants. By the eighth focus group, data saturation was reached. In accordance with established guidelines,⁶⁵ a ninth focus group was conducted to confirm that the overall frequency counts were an accurate representation for the population.

RESULTS

Two overarching themes were discussed within the focus group sessions, barriers (66%), and supports (34%) to obtaining services within the military healthcare system, as well as within the community (see Table 2). Barriers and supports were discussed for both caregivers and their SMVs. A breakdown of this thematic content is summarized next.

Barriers to services

Barriers to obtaining services were the most frequent topic of discussion (66% of the discussion about services). Caregivers often mentioned the SMVs' barriers to healthcare (50%), their own barriers (34%), barriers to family care (5%), and community organizations (5%).

Barriers to healthcare for SMV (50%)—Caregivers indicated several barriers to their SMVs healthcare including (1) access to services (“He’s still fighting to get his TBI documented”); (2) quality of the care provided (“Now he’s got the machine, it’s not adjusted right, so he can’t breathe . . . he has to wait another two or three months to get an appointment to get it adjusted”); and (3) financial burden (“ . . . even at 100% rating, and getting your caregiver stipend, if you own a home and you have a car payment and you have bills, you’re not making ends meet”).

1. *1. Barriers to access to services for SMV.* Caregivers reported that their SMVs' access to services varied depending upon injury documentation (ie, recipient of a Purple Heart award), diagnosis, and TBI disability severity rating. For example, the process of receiving a TBI diagnosis and associated benefits was reported to be both a slow and a cumbersome process (“It took over two years and it took me going to the Surgeon General and the Vice Chief of Staff twice to get this diagnosed”). Caregivers also indicated how the transition from active duty to civilian life, and/or from the DoD to the VA Health Care System, frequently results in gaps in SMV treatment (“I was taking care of him, and the VA hadn’t come through yet . . . so we didn’t have any health care”).

Furthermore, common concerns with service members' access to services included the inability to get a timely appointment (“We just had to wait from August to January to get a neurology appointment”), time commitment of the appointments due to the lack of proximity to the care facilities (“He’d rather sit at home, lay on the floor in pain because it’s not always possible to drive . . . a 6¹/₂ or 7¹/₂ hour round trip whenever you’re suffering”), difficulty for caregivers who are not beneficiaries in getting onto a base to bring an SMV to an appointment (“As non-spouse family members, we receive no benefits. We receive no access. We receive nothing.”), burden of paperwork (“You have to wade through filling out the paperwork and submitting the paperwork.”), and difficulty in navigating either the VA or DoD systems to receive care (“It would be really nice if we actually could know what the services are... It’s like a scavenger hunt . . .”).

1. *2. Barriers to quality services for SMV.* With regard to the services provided to the SMVs, caregivers referenced the poor quality of treatments received (“they’re rude, they treat him like they’re doing him some kind of favor”). Specifically, caregivers expressed that SMVs felt a lot of their medical issues were overlooked and were often told their problems were simply “in their head.” Lack of communication among care providers was also a concern and there was generally consensus that the services had a slow response time, both with scheduling appointments and fixing malfunctioning at-home medical equipment.

2. 3. *Financial barriers for SMV.* Given that the transition from active duty to civilian life can be complicated, and the compensation process can be associated with gaps in care (mentioned earlier), this transition can also be a time of extreme financial hardship (“We went 120 days with no pay at all. Zero. So he got out and we had nothing. We own a home, we had two car payments. We have bills. We have four kids.”).

Barriers to Healthcare for the caregiver (34%)—Caregivers discussed their concerns with access to services for themselves. Themes included caregiver status and recognition, health insurance (“And through . . . the caregiver program, we’re supposed to get healthcare. But we don’t know if we’re going to end up qualifying for it”), quality of the care provided (eg, counseling, care giver coordinators; “it took me 6¹/₂ months and my care giver coordinator never helped”), financial burden (“It ends up to be like \$2100.00 a month. That doesn’t even cover my mortgage.”), and advocacy issues (“we had to fight from the very beginning”).

Barriers to family care (5%) and barriers to community organizations (5%)—Less frequently, caregivers discussed barriers to family care for children of these SMVs including unmet healthcare needs (“We can’t get the care for emotional health for our children”), and child care coverage to allow the SMV and caregiver to attend medical appointments (“We need babysitting at the VA”). In addition, caregivers also discussed barriers to community organizations (“There’s no linkage between the caregiver and the organization or a company that wants to help”).

Supports

Supports to obtaining services comprised 34% of the caregivers’ discussions about services. Within these discussions, caregivers often mentioned the SMVs’ health-care (38%), community organizations (25%), their own healthcare (24%), and supports to obtaining family care (5%).

Supports for SMV healthcare (38%)—With regard to SMV supports, caregivers discussed financial support (“they have all of these things available. Like they’ll pay for modifications for your home”), support scheduling appointments (“within two days I had phone calls and new appointments scheduled”), proximity to services (“We only live 30 minutes from the VA”), and easy access to services such as therapy, lawyers, and treatments (“I love my FRC [Federal Resource Coordinator]. I can call her at 10:00 at night . . . and say, ‘Are you still in your office?’ She’s like, ‘I’m always in my office.’”). In addition, as previously mentioned, documented injury (ie, recipient of a Purple Heart) and diagnosis are critical for ensuring that the SMV receives appropriate care (“He’s a Purple Heart recipient, so all of his care is taken care of”).

Supports for caregiver healthcare (24%)—With regard to their own healthcare, caregivers specifically referenced caregiver stipends (“it is an absolute integral part of my family dynamic to be able to have that stipend”), care coordination (“We have great care coordinators”), support groups (“It’s through the VA. It’s a new caregiver program they do.

And I love it. I go once a month”), and health insurance (“My health care is through CHAMPVA through the caregiver program”), as well as access to counseling (“thank God for the counseling that the caregiver program provides”).

Supports provided by community organizations (25%)—In addition, caregivers discussed how community organizations were a helpful resource in obtaining services. The organizations most frequently discussed were Operation Home Front-Hearts of Valor (“We went through a program Operation Home front, and we were awarded a mortgage free home”), the Wounded Warrior Project (“[the] Wounded Warrior Project—they’re the only people that have ever done anything for me”), Coalition to Salute America’s Heroes (“They’ll employ wounded warrior wives”), and Operations Finally Home (“there’s Operation Finally Home, which provides homes for wounded warriors, depending on their injuries and things like that”). These organizations provided the care givers with supports, such as sponsored respite care (“He’s doing a trip in July where he’s going to the Colorado River”) and outreach through transitions home (“licensed mental health professionals that come to your home”).

Supports for family care (5%)—Less frequently, caregivers discussed family care (“ . . . most of our services now that we do seek is beneficial to the kids . . . I don’t want them to feel like we tried to keep it from them. So now it’s kinda more of opening up to them about it”).

DISCUSSION

These focus groups highlighted the diversity of perceptions and experiences of caregivers in accessing care for their SMVs. While there are numerous services and supports available to SMVs with TBI and their families, there are also a number of challenges that caregivers experience accessing these services. For SMVs with a TBI, the system can be very difficult to navigate, even with the assistance of a caregiver. Not surprisingly, caregivers face numerous challenges navigating the military healthcare system and perceive unmet needs with regard to health services for both themselves and the SMV they care for. This often includes barriers accessing healthcare, quality of the care provided, and financial burden for both the service member and caregiver themselves.

The process of accessing services can be especially challenging when there is not adequate clinical and administrative documentation to support a judgment of eligibility for services. What may appear to be a slow process can increase frustration and anger when the SMV or caregiver has not been adequately informed about what is happening or is experiencing urgent unmet needs. Obtaining the necessary medical documentation may require visits with multiple providers. Even after a successful transition to the VA Health Care System, common caregiver complaints included the inability to get a timely appointment, time commitment of the appointments due to the lack of proximity to the care facilities, difficulty for caregivers who are not beneficiaries in getting onto a base to bring a service member to an appointment (for those receiving DoD care), burden of paperwork, and difficulty in navigating either the VA or DoD systems to receive care. These common complaints are

consistent with already identified barriers to treatments within the scientific literature.
47,54,55,57,58,72–74

In addition to the concerns highlighted about the SMVs' care, there was also discussion on the barriers that the caregivers themselves encounter within the military healthcare system. Consistent with the literature, there are a number of unmet family and spousal needs that these caregivers encounter^{54–58} and a general lack of knowledge about where to get services.^{55,57,58} In addition, narratives highlighted a general lack of services for the caregivers themselves. While initiatives are underway to characterize and address these caregiver-specific needs (including the family Caregiver Curriculum,⁷⁵ Caregivers of Veterans report,⁷⁶ the 15-year longitudinal study to evaluate military-related TBI and the effects on their family members,⁷⁷ and the VA Caregiver Support Program),⁷⁸ there is still much work to do in improving the health-related quality of life of these caregivers and their SMVs.

While much of the discussion focused on the different barriers that caregivers experienced and areas where they believed improvements could be made, these caregivers also recognized a number of supports that they and their SMV receive both within the military healthcare system and the broader community. For example, there was a genuine appreciation for the cutting-edge medical care and diverse treatments that were available for SMVs with TBI. There was also a discussion of how important the caregiver stipend was for these individuals, and how this helps them keep their SMV at home and allows the caregiver the opportunity to give back (to both the service member and their country) by being able to provide care to their SMV themselves. The care coordinator was identified as a key support to navigating and accessing services within the VA Health Care System, as well as within the broader community. There was also a lot of discussion and praise given to multiple community organizations and the supports and services they provide for both the SMVs and their families.

Limitations

While this article exhibits a number of strengths, it is also important to recognize several limitations. First, it was often difficult for nonmilitary research personnel to access military medical records; thus, medical documentation of TBI was not available for 20% of our sample. We also do not have objective data to substantiate specific healthcare complaints (eg, healthcare utilization or benefit information). In addition, in some cases, although adequate care may have been provided, the service members and their caregivers may have unmet needs that reflect the severity of their injuries, the emotional turmoil that they continue to suffer, or other factors. Furthermore, since pain, posttraumatic stress, mood changes, and other conditions are prevalent in this population, it is difficult to disentangle the relative contribution of each condition to overall functioning or the ability to access services. We also used an analytic approach that was developed to quantify discussion topics (ie, latent content analysis) rather than a more traditional qualitative analysis (eg, narrative analysis), which rely more heavily on coder interpretation and are focused on identifying underlying meaning and examining the complex interrelationships among identified thematic areas.^{66–68,79} Finally, generalizability of findings is limited by the overall representation of the sample. More research focusing on parent and child caregivers of

military-related TBI, as well as male caregivers and those caregivers who are older adults, is needed to ensure generalizability of findings to these groups.

CONCLUSIONS

Regardless of these limitations, it is apparent that caregivers confront numerous challenges while pursuing healthcare services. Thus, attention to increasing accessibility and quality of services, as well as reducing financial burden, can lead to improved health-related quality of life for the caregiver and their SMV. Many of these efforts are underway and have been established as a priority within the military healthcare system to address the needs of this most deserving population.

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APPENDIX 1: TBI-CareQOL military caregiver access to care questions

- a. Tell us about your ability to get the services, programs, or support (ie, healthcare, 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 healthcare needs of the person you care for.
- 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?

APPENDIX 2: Qualitative frequency analysis codebook for barriers and supports to military health care services

Primary node	Secondary node	Tertiary node	Quaternary node	Node description
Respite				Include any nonspecific reference to respite regardless of source of

Primary node	Secondary node	Tertiary node	Quaternary node	Node description
	Not wanting respite care			respite (eg, VA and community) Include references to not needing or wanting respite care
		Caregiver not wanting		Include direct references to the caregiver not wanting respite services because alternative care is not optimal
		Service member not wanting		Include direct references to the SMV not wanting respite services due to distrust in strangers or other reasons
	Barriers			Include ineligibility for respite care or care provided not being in line with the needs of the SMV or caregiver
	Supports			Include positive references to respite care
Barriers				Include nonspecific reference to barriers to healthcare services
	SMV medical/ physical/ mental healthcare			Include broad references to SMV poor quality of care
		Access to services		Include nonspecific references with regard to barriers to healthcare access, including disability rating, diagnosis, and Purple Heart award
			Time commitment and proximity to services	Indication that distance to care facility is prohibitive and/or that the amount of time required to get to and be seen for the appointment is prohibitive
			Cost	References that indicate that it is too expensive to seek care

Primary node	Secondary node	Tertiary node	Quaternary node	Node description
			Insurance	Include references to actual benefits and service connection percentages, as well as threats to losing benefits; barriers can also include burden of paperwork and difficulty navigating the system
			Scheduling	Include things such as being unable to get a timely appointment, being given appointment times at the last minute, as well as difficulties for noncaregivers in getting onto base to bring service member to appointments
		Services provided		Include any negative reference to services that the SMV receives and/or is qualified for; also include references to stigma related to SMV healthcare; references can be about barriers to appointments, treatment, resources, therapy, or access to lawyers
		Compensation		Include negative references about compensation (eg, lack of reimbursement for travel and interruptions in disability compensation)
	Community organizations			Include negative references to community organizations, support groups, sponsored respite care through community organization; outreach during transition home
	Caregiver medical/physical/mental healthcare			General statements of difficulties

Primary node	Secondary node	Tertiary node	Quaternary node	Node description
				associated with being a caregiver, including lack of understanding, stigma, and difficulty finding and sharing information
		Advocacy		Include instances of needing to advocate for either their own care or that of their SMV
		Access to services		Include difficulties accessing care due to not being married to service member (nonmarried partner or parent); no private health insurance; too expensive to seek care; treatment too far away
			Cost	Too expensive to seek care, not being reimbursed for travel
			Insurance	Not being married to service member; no private health insurance; lack of satisfaction with insurance provided
			Role recognition and understanding	Include references about a lack of recognition related to care provided; include threats to losing their status/benefits
		Services provided		Include references to services that the caregiver qualifies for or has access to; include counseling, caregiver coordinators, training, and resources
		Compensation		Include negative references to caregiver stipend
	Family care/kids			Include unmet needs for children of SMV; this includes negative

Primary node	Secondary node	Tertiary node	Quaternary node	Node description
				experiences with family relocation due to proximity to treatment; kids not able to access base during early phases of treatment; kids needing help understanding service member's injury; barriers to benefits for these children; lack of medical care or counseling for children
		Spouse/partner combined care		Include references that indicate barriers to combined care for spouse and SMV (eg, inability to schedule appointments together)
Supports				Include nonspecific positive references to healthcare services
	SMV medical/ physical/ mental healthcare			Include broad references to SMV high-quality care
		Access to services		Include nonspecific references with regard to positive experiences with healthcare access, including disability rating, Purple Heart award, and timely diagnosis
			Time commitment and proximity to services	Positive references that appointments are efficient and that treatment location is close and convenient
			Cost	References that healthcare is affordable and costs are reasonable
			Insurance	Positive references to having adequate benefits and service connection percentages

Primary node	Secondary node	Tertiary node	Quaternary node	Node description
			Scheduling	Positive references about flexibility and ease of scheduling healthcare appointments
		Services provided		Include any positive reference to services that the SMV receives and/or is qualified for; references can be about appointments, treatment, resources, therapy, or access to lawyers
		Compensation		Include positive references to disability compensation
	Community organizations			Include general references to community organizations, support groups, sponsored respite care through community organizations; include positive experiences with community outreach during transition home
		Operation Finally Home		Positive experiences with Operation Finally Home
		Coalition to Support America's Heroes		Positive experiences with Coalition to Support America's Heroes
		Operation Home Front		Positive experiences with Operation Home Front
			Hearts of Valor	Positive experiences with Hearts of Valor
		Wounded Warrior Project		Positive experiences with Wounded Warrior Project
	Caregiver medical/physical/mental healthcare			Include broad references to caregiver's positive experiences with healthcare
		Access to services		Include references to

Primary node	Secondary node	Tertiary node	Quaternary node	Node description
				caregiver access to benefits, including status as a caregiver within the healthcare system
			Cost	Include reference to affordable care
			Insurance	Include access to insurance for the caregiver
			Role recognition and understanding	Include positive statements about caregiver recognition and appreciation
		Services provided		Include positive references to caregiver coordinator, physical healthcare, medications, and mental healthcare; also include references to resources, education, and support provided to caregiver
		Compensation		Include any positive reference to caregiver stipend
	Family care/kids			Include positive experience for the needs for children of SMV; include positive experiences with family relocation and access to healthcare services for children
		Spouse/partner combined care		Include references that support combined care for spouse and SMV (eg, being able to be seen together and doctors taking the time to talk with both the SMV and caregiver); include positive references about healthcare providers inquiring about caregiver health during SMV appointment

REFERENCES

1. DVVIC. DoD Worldwide Numbers for TBI. <http://dvbic.dcoe.mil/dod-worldwide-numbers-tbi>. Published 2015 Accessed October 2, 2017.
2. Hoge CW, McGurk D, Thomas JL, Cox AL, Engel CC, Castro CA. Mild traumatic brain injury in U.S. soldiers returning from Iraq. *N Engl J Med*. 2008;358(5):453–463. [PubMed: 18234750]
3. Nampiaparampil DE. Prevalence of chronic pain after traumatic brain injury: a systematic review. *JAMA*. 2008;300(6):711–719. [PubMed: 18698069]
4. Traumatic Brain Injury Model Systems National Data Center. Traumatic Brain Injury Model Systems National Data Base Inclusion Criteria. <http://www.tbinsc.org/Documents/2010%20TBIMS%20Slide%20Presentation.pdf>. Published 2006 Accessed October 2, 2017.
5. The Management of Concussion/mTBI Working Group. VA/DoD Clinical Practice Guideline for Management of Concussion/Mild Traumatic Brain Injury (mTBI). *J Rehabil Res Dev*. 2009;46(6):CP1–CP68.
6. Schofield PW, Moore TM, Gardner A. Traumatic brain injury and olfaction: a systematic review. *Front Neurol*. 2014;5:5. [PubMed: 24478752]
7. Sigurdardottir S, Andelic N, Skandsen T, et al. Olfactory identification and its relationship to executive functions, memory, and disability one year after severe traumatic brain injury. *Neuropsychology*. 2016;30(1):98–108. [PubMed: 26076319]
8. Frasnelli J, Lague-Beauvais M, LeBlanc J, et al. Olfactory function in acute traumatic brain injury. *Clin Neurol Neurosurg*. 2016;140:68–72. [PubMed: 26658033]
9. Whyte J, Hart T, Laborde A, Rosenthal M. Rehabilitation issues in traumatic brain injury In: DeLisa J, Gans B, eds. *Physical Medicine and Rehabilitation: Principles and Practice*. 4 ed Philadelphia, PA: Lippincott, Williams and Wilkins; 2005.
10. Palacios EM, Sala-Llonch R, Junque C, et al. Long-term declarative memory deficits in diffuse TBI: correlations with cortical thickness, white matter integrity and hippocampal volume. *Cortex*. 2012;49(3):646–657. [PubMed: 22482692]
11. West LK, Curtis KL, Greve KW, Bianchini KJ. Memory in traumatic brain injury: the effects of injury severity and effort on the Wechsler Memory Scale-III. *J Neuropsychol*. 2011;5(pt 1):114–125. [PubMed: 21366889]
12. Cicerone KD, Smith LC, Ellmo W, et al. Neuropsychological rehabilitation of mild traumatic brain injury. *Brain Inj*. 1996;10(4):277–286. [PubMed: 9044693]
13. Cicerone KD, Langenbahn DM, Braden C, et al. Evidence-based cognitive rehabilitation: updated review of the literature from 2003 through 2008. *Arch Phys Med Rehabil*. 2011;92(4):519–530. [PubMed: 21440699]
14. Cicerone KD, Dahlberg C, Kalmar K, et al. Evidence-based cognitive rehabilitation: recommendations for clinical practice. *Arch Phys Med Rehabil*. 2000;81(12):1596–1615.
15. Cicerone KD, Dahlberg C, Malec JF, et al. Evidence-based cognitive rehabilitation: updated review of the literature from 1998 through 2002. *Arch Phys Med Rehabil*. 2005;86(8):1681–1692. [PubMed: 16084827]
16. Dikmen S, Corrigan JD, Levin HS, Machamer J, Stiers W, Weisskopf MG. Cognitive outcome following traumatic brain injury. *J Head Trauma Rehab*. 2009;24(6):430–438.
17. Grafman J, Schwab K, Warden D, Pridgen A, Brown HR, Salazar AM. Frontal lobe injuries, violence, and aggression: a report of the Vietnam Head Injury Study. *Neurology*. 1996;46(5):1231–1238. [PubMed: 8628458]
18. Agitation Kim E., aggression, and disinhibition syndromes after traumatic brain injury. *NeuroRehabilitation*. 2002;17(4):297–310. [PubMed: 12547978]
19. Hibbard MR, Uysal S, Kepler K, Bogdany J, Silver J. Axis I psychopathology in individuals with traumatic brain injury. *J Head Trauma Rehabil*. 1998;13(4):24–39. [PubMed: 9651237]
20. Brown M, Gordon WA, Spielman L. Participation in social and recreational activity in the community by individuals with traumatic brain injury. *Rehabil Psychol*. 2003;48(4):266–274.

21. Verhaeghe S, Defloor T, Grypdonck M. Stress and coping among families of patients with traumatic brain injury: a review of the literature. *J Clin Nurs*. 2005;14(8):1004–1012. [PubMed: 16102152]
22. Dausch BM, Saliman S. Use of family focused therapy in rehabilitation for veterans with traumatic brain injury. *Rehabil Psychol*. 2009;54(3):279–287. [PubMed: 19702426]
23. McFarlane AC. Military deployment: the impact on children and family adjustment and the need for care. *Curr Opin Psychiatry*. 2009;22(4):369–373. [PubMed: 19424067]
24. Ponsford J, Olver J, Ponsford M, Nelms R. Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Inj*. 2003;17(6):453–468. [PubMed: 12745702]
25. Sander AM, Caroselli JS, High WM, Becker C, Neese L, Scheibel R. Relationship of family functioning to progress in a post-acute rehabilitation programme following traumatic brain injury. *Brain Inj*. 2002;16(8):649–657. [PubMed: 12182162]
26. McLaughlin AM, Carey JL. The adversarial alliance: developing therapeutic relationships between families and the team in brain injury rehabilitation. *Brain Inj*. 1993;7(1):45–51. [PubMed: 8425115]
27. Pelletier PM, Alfano DP. Depression, social support, and family coping following traumatic brain injury. *Brain Cogn*. 2000; 44(1):45–49.
28. Florian V, Katz S, Lahav V. Impact of traumatic brain damage on family dynamics and functioning: a review. *Brain Inj*. 1989;3(3):219–233. [PubMed: 2667675]
29. Sander AM, Maestas KL, Sherer M, Malec JF, Nakase-Richardson R. Relationship of caregiver and family functioning to participation outcomes after postacute rehabilitation for traumatic brain injury: a multicenter investigation. *Arch Phys Med Rehabil*. 2012;93(5):842–848. [PubMed: 22417896]
30. Sady MD, Sander AM, Clark AN, Sherer M, Nakase-Richardson R, Malec JF. Relationship of preinjury caregiver and family functioning to community integration in adults with traumatic brain injury. *Arch Phys Med Rehabil*. 2010;91(10):1542–1550. [PubMed: 20875512]
31. Vangel SJ, Jr, Rapport LJ, Hanks RA. Effects of family and caregiver psychosocial functioning on outcomes in persons with traumatic brain injury. *J Head Trauma Rehabil*. 2011;26(1):20–29. [PubMed: 21209560]
32. Smith AM, Schwirian PM. The relationship between caregiver burden and TBI survivors' cognition and functional ability after discharge. *Rehabil Nurs*. 1998;23(5):252–257. [PubMed: 10067640]
33. Halldorsson JG, Flekkoy KM, Arnkelsson GB, Tomasson K, Magnadottir HB, Arnarson EO. The scope of early traumatic brain injury as a long-term health concern in two nationwide samples: prevalence and prognostic factors. *Brain Inj*. 2012;26(1):1–13. [PubMed: 22149441]
34. Institute of Medicine. *Gulf War and Health: Volume 7. Long-Term Consequences of Traumatic Brain Injury*. Washington, DC: National Academies Press; 2008.
35. Ponsford J, Draper K, Schonberger M. Functional outcome 10 years after traumatic brain injury: its relationship with demographic, injury severity, and cognitive and emotional status. *J Int Neuropsychol Soc*. 2008;14(2):233–242. [PubMed: 18282321]
36. Thurman DJ, Alverson C, Dunn KA, Guerrero J, Sniezek JE. Traumatic brain injury in the United States: a public health perspective. *J Head Trauma Rehabil*. 1999;14(6):602–615. [PubMed: 10671706]
37. Vangel SJ, Jr, Rapport LJ, Hanks RA, Black KL. Long-term medical care utilization and costs among traumatic brain injury survivors. *Am J Phys Med Rehabil*. 2005;84(3):153–160. [PubMed: 15725788]
38. Kolakowsky-Hayner SA, Miner KD, Kreutzer JS. Long-term life quality and family needs after traumatic brain injury. *J Head Trauma Rehabil*. 2001;16(4):374–385. [PubMed: 11461659]
39. Ponsford J, Schonberger M. Family functioning and emotional state two and five years after traumatic brain injury. *J Int Neuropsychol Soc*. 2010;16(2):306–317. [PubMed: 20128950]
40. French LM, Parkinson GW, Massetti S. Care coordination in military traumatic brain injury. *Social Work in Health Care*. 2011;50(7):501–514. [PubMed: 21846251]

41. Helmick KM, Spells CA, Malik SZ, Davies CA, Marion DW, Hinds SR. Traumatic brain injury in the US military: epidemiology and key clinical and research programs. *Brain Imaging Behav.* 2015;9(3):358–366. [PubMed: 25972118]
42. Scholten J, Cernich A, Hurley RA, Helmick K. Department of Veterans Affairs' Traumatic Brain Injury Screening and Evaluation Program: Promoting Individualized Interdisciplinary Care for Symptomatic Veterans. *J Head Trauma Rehab.* 2013;28(3):219–222.
43. Cozza SJ, Goldenberg M, Ursano RJ, American Psychiatric Association Care of Military Service Members, Veterans, and Their Families. 1st ed Washington, DC: American Psychiatric Publishing; 2014.
44. Scott SG, Belanger HG, Vanderploeg RD, Massengale J, Scholten J. Mechanism-of-injury approach to evaluating patients with blast-related polytrauma. *J Am Osteopath Assoc.* 2006;106(5):265–270. [PubMed: 16717367]
45. Chokshi DA. Improving health care for veterans—a watershed moment for the VA. *N Engl J Med.* 2014;371(4):297–299. [PubMed: 24896820]
46. Schall MW, Duffy T, Krishnamurthy A, et al. Improving patient access to the Veterans Health Administration's primary care and specialty clinics. *Jt Comm J Qual Saf.* 2004;30(8):415–423. [PubMed: 15357131]
47. Elnitsky CA, Andresen EM, Clark ME, McGarity S, Hall CG, Kerns RD. Access to the US Department of Veterans Affairs health system: self-reported barriers to care among returnees of Operations Enduring Freedom and Iraqi Freedom. *BMC Health Serv Res.* 2013;13:498. [PubMed: 24289747]
48. Stecker T, Fortney JC, Hamilton F, Ajzen I. An assessment of beliefs about mental health care among veterans who served in Iraq. *Psychiatr Serv.* 2007;58(10):1358–1361. [PubMed: 17914017]
49. Chapman PL, Elnitsky C, Pitts B, Figley C, Thurman RM, Unwin B. Mental health, help seeking, and stigma and barriers to care among 3- and 12-month postdeployed and never deployed U.S. Army Combat Medics. *Mil Med.* 2014;179(8 suppl):55–62. [PubMed: 25102550]
50. Elnitsky CA, Chapman PL, Thurman RM, Pitts BL, Figley C, Unwin B. Gender differences in combat medic mental health services utilization, barriers, and stigma. *Mil Med.* 2013;178(7): 775–784. [PubMed: 23820352]
51. Mittal D, Drummond KL, Blevins D, Curran G, Corrigan P, Sullivan G. Stigma associated with PTSD: perceptions of treatment seeking combat veterans. *Psychiatr Rehabil J.* 2013;36(2):86–92. [PubMed: 23750758]
52. Blais RK, Renshaw KD. Stigma and demographic correlates of help-seeking intentions in returning service members. *J Trauma Stress.* 2013;26(1):77–85. [PubMed: 23335155]
53. Zinzow HM, Britt TW, McFadden AC, Burnette CM, Gillispie S. Connecting active duty and returning veterans to mental health treatment: interventions and treatment adaptations that may reduce barriers to care. *Clin Psychol Rev.* 2012;32(8):741–753. [PubMed: 23063627]
54. Misra-Hebert AD, Santurri L, DeChant R, et al. Understanding the health needs and barriers to seeking health care of veteran students in the community. *South Med J.* 2015;108(8):488–493. [PubMed: 26280777]
55. Lewy CS, Oliver CM, McFarland BH. Barriers to mental health treatment for military wives. *Psychiatr Serv.* 2014;65(9):1170–1173. [PubMed: 24933260]
56. Verdelli H, Baily C, Voursoura E, Belser A, Singla D, Manos G. The case for treating depression in military spouses. *J Fam Psychol.* 2011;25(4):488–496. [PubMed: 21842994]
57. Gorman LA, Blow AJ, Ames BD, Reed PL. National Guard families after combat: mental health, use of mental health services, and perceived treatment barriers. *Psychiatr Serv.* 2011;62(1):28–34. [PubMed: 21209296]
58. Eaton KM, Hoge CW, Messer SC, et al. Prevalence of mental health problems, treatment need, and barriers to care among primary care-seeking spouses of military service members involved in Iraq and Afghanistan deployments. *Mil Med.* 2008;173(11):1051–1056. [PubMed: 19055177]
59. Cella DF. Measuring quality of life in palliative care. *Semin Oncol.* 1995;22(2 suppl 3):73–81. [PubMed: 7537908]

60. Carlozzi NE, Brickell TA, French LM, et al. Caring for our wounded warriors: a qualitative examination of health-related quality of life in caregivers of individuals with military-related traumatic brain injury. *J Rehabil Res Dev*. 2016;53(6):669–680. [PubMed: 27997672]
61. PROMIS. PROMIS © Instrument Development and Psychometric Evaluation Scientific Standards. <http://www.nihpromis.org/Documents/PROMISStandards050212.pdf>. Accessed October 2, 2017.
62. Jarrett RL. Living poor—family-life among single-parent, African-American women. *Soc Probl*. 1994;41(1):30–49.
63. Jarrett RL. Focus group interviewing with low-income minority populations: a research experience In: Morgan DL, ed. *Successful Focus Groups: Advancing the State of the Art*. Newbury Park, CA: Sage; 1993:184–201.
64. Stewart DW, Shamdasani PN. *Focus Groups: Theory and Practice* London, England: Sage; 1990.
65. Kisala P, Tulsy D. Opportunities for CAT applications in medical rehabilitation: development of targeted item banks. *J Appl Meas*. 2010;11(3):315–330. [PubMed: 20847478]
66. Catanzaro M Using qualitative analytical techniques In: Wood NF, Catanzaro M, eds. *Nursing Research: Theory and Practice*. St Louis, MO: The C.V. Mosby Company; 1988.
67. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–1288. [PubMed: 16204405]
68. Miles MB, Huberman AM, Saldana J. *Qualitative Data Analysis: A Methods Sourcebook*. 3rd ed Thousand Oaks, CA: Sage Publications, Inc; 2014.
69. Basch CE. Focus group interview: an underutilized research technique for improving theory and practice in health education. *Health Educ Q*. 1987;14(4):411–448. [PubMed: 3319971]
70. Basch CE, DeCicco IM, Malfetti JL. A focus group study on decision processes of young drivers: reasons that may support a decision to drink and drive. *Health Educ Q*. 1989;16(3): 389–396. [PubMed: 2793494]
71. Zemke R, Kramlinger T. *Figuring Things Out*. Reading, MA: Addison-Wesley; 1985.
72. Kim PY, Thomas JL, Wilk JE, Castro CA, Hoge CW. Stigma, barriers to care, and use of mental health services among active duty and National Guard soldiers after combat. *Psychiatr Serv*. 2010;61(6):582–588. [PubMed: 20513681]
73. Hoge CW, Castro CA, Messer SC, McGurk D, Cotting DI, Koffman RL. Combat duty in Iraq and Afghanistan, mental health problems and barriers to care. *US Army Med Dep J*. 2008;7–17. [PubMed: 20088060]
74. Fletcher CE, Mitchinson AR, Trumble E, Hinshaw DB, Dusek JA. Providers' and Administrators' Perceptions of Complementary and Integrative Health Practices Across the Veterans Health Administration. *J Altern Complement Med*. 2017;23(1):26–34. [PubMed: 27925776]
75. Parkkinen L, Kauppinen T, Pirttila T, Autere JM, Alafuzoff I. Alpha-synuclein pathology does not predict extrapyramidal symptoms or dementia. *Ann Neurol*. 2005;57(1):82–91. [PubMed: 15562510]
76. Caregiving NA National Alliance for Caregiving. *Caregivers of Veterans—Serving on the Homefront: Report of Study Findings*. Bethesda, MD: National Alliance for Caregiving; 2010.
77. United States Government Publishing Office. 109th Congress. John Warner National Defense Authorization Act for Fiscal Year 2007; Sec. 721. <http://www.gpo.gov/fdsys/pkg/BILLS-109hr5122enr/pdf/BILLS-109hr5122enr.pdf>. Accessed October 2, 2017.
78. U.S. Department of Veterans Affairs. <https://www.caregiver.va.gov/>. Accessed October 2, 2017.
79. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24(2):105–112. [PubMed: 14769454]

TABLE 1

Demographic data for caregivers and service members and veterans (N = 45)

Variable	Value
<i>Caregiver</i>	
Age, y	
Mean (SD)	37.3 (9.6)
Sex	
Female, <i>n</i> (%)	42 (93)
Relationship to SMV, <i>n</i> (%)	
Spouse	33 (73)
Child	7(16)
Parent	2(4)
Other	3(7)
Time in caregiver role, y	
Mean (SD)	4.4 (2.5)
<i>SMV</i>	
Service member age, y	
Mean (SD)	34.6 (6.4)
Service member sex, <i>n</i> (%)	
Female	2(4)
TBI severity, <i>n</i> (%)	
Mild	22 (49)
Moderate	6(13)
Severe	3(7)
Penetrating	5(11)
Unknown	9(20)
Service branch, <i>n</i> (%)	
Army	30 (67)
Marine Corps	5(11)
Army National Guard	3(7)
Air Force	2(4)
Army Reserves	2(4)
Navy	2(4)
Navy Reserves	1 (2)
Active duty	
Yes, <i>n</i> (%)	4(9)
Blast-related injuries	
Yes, <i>n</i> (%)	30 (67)
Mechanism of injury, <i>n</i> (%)	
Motor vehicle accident	19(42)
Gunshot wound	7(16)
Thrown against object	6(13)

Variable	Value
Fall	3(7)
Struck by object	3(7)
Multiple mechanisms	4(9)
Other	1 (2)
Deployment-related injury, <i>n</i> (%)	
Yes—combat-related	31 (69)
Yes—non-combat-related	6(13)
No—not deployment-related	6(13)
More than 1 option (multiple injuries)	2(4)

Abbreviations: SD, standard deviation; SMVs, service members and veterans; TBI, traumatic brain injury.

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TABLE 2

Barriers and supports to military healthcare services generated among caregivers of service members and veterans with a military-related traumatic brain injury^a

Barriers and supports to military healthcare services by subtype	Example quotation	Overall thematic breakdown (% of discussion)
Barriers		<i>66%</i>
Service members	“We waited about six months to try to get him an appointment ‘cause he was having problems breathing.”	(50)
Caregiver	“I’ve applied for Caregiver three times and been denied”	(34)
Community organizations	“Anyone that offers caregiver services they look at me and they say ‘You’re not a real caregiver. You’re not caregiver enough.’”	(5)
Family care	“I know it’s been hard to get like family type counseling. I think that has been the hardest thing. Like it’s like trying to pull teeth ... it seems like everything’s a fight as far as like family type stuff.”	(5)
Supports		<i>34%</i>
Service members	“There was counseling available; we went three times a week. I mean, we had just amazing—and we had top-notch care.”	(38)
Community organizations	“Amazing. I mean they’ve changed my husband’s entire perspective on just like life”	(25)
Caregiver	“VA [Veterans Affairs] caregiver coordinators, I guess is what they’re called. They’ve been very helpful. Anything I needed, like respite care arrangements, anything with counseling, if I had a question. They’ve always sent me e-mails to make sure I was aware of the conferences that they would have every year, so I take advantage of that.”	(24)
Family care	“We’ve also had sessions for our kids to go so that they can understand more of what he’s going through.”	(5)

^aPercentages for domains reflect the total percentage of comments related to this specific domain (domain percentages in italic sum to 100%); percentages within each subdomain are indicated within parentheses and reflect the percentage of comments within each domain (should sum to < 100 since content was only included that fit within that subdomain; other content would only be included in the total domain percentage). Participant comments as they appear in this article were directly quoted, and may therefore not reflect strict grammatical rules.