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Perception of Barriers to Diagnosis and Receipt of Treatment for Neuropsychiatric Disturbances Following Traumatic Brain Injury

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Abstract

Objective: To explore perceptions of barriers and facilitators to diagnosis and receipt of treatment for neuropsychiatric disturbances (NPD) following traumatic brain injury (TBI).

Design: Qualitative study employing semi-structured interviews and focus groups

Setting: A clinic specializing in the treatment of TBI NPD, an urban trauma center, and a large urban academic hospital

Participants: Ten health care providers who treat individuals with TBI, 18 persons with TBI and 5 caregivers

Main Outcome Measures: Topic guides for the interviews and focus groups were guided by prior literature, clinical experience, and the goals of the project and focused on the three most common TBI NPD: depression, anxiety, and post-traumatic stress disorder. Interviews and focus groups were audio-recorded and transcribed. We performed a conventional content analysis on the transcripts and grouped concepts into overall themes, incorporating feedback from stakeholders.

Results: Patient education, insurance, provider type, time since TBI, caregiver support, and recognition or screening for TBI NPD were the most frequently mentioned barriers or facilitators to diagnosis and treatment of TBI NPD by both interview and focus group participants. We grouped these and other frequently mentioned concepts into three broad themes: education, access, and support. Each of these themes is explored in depth and supported with direct quotations.

Conclusions: This study explored patient, caregiver and health care provider – identified barriers and facilitators to the diagnosis and receipt of treatment for TBI NPD. Barriers included poor provider education on TBI NPD and limited access to care due to lack of insurance, transportation, and income. Facilitators included patient education on TBI NPD and strong caregiver support. Future studies should develop and pilot interventions aimed at quality of care that address the identified barriers and facilitators.

Keywords

Traumatic brain injury; Neuropsychiatric disturbance; Qualitative study; Barriers to receipt of treatment

Introduction

Over 2.5 million traumatic brain injuries (TBI) are diagnosed each year in the United States and it is estimated that close to an equal number are unreported or undiagnosed.^{1,2} Neuropsychiatric disturbances (NPD) are common following TBI (prevalence 7%–46%) and associated with decreased cognitive and functional recovery and poorer quality of life.^{3–11} TBI NPD may result from trauma to brain regions involved in emotional regulation and behavioral control as well as other environmental and psychosocial stressors such as loss of employment, increased dependence on others for day-to-day functioning, financial strain and lack of family support and/or social network.^{12–15} Even so, diagnosis of NPD following TBI is challenging due to the lack of established criteria for distinguishing disorders, differences in instruments used to capture NPD, time since TBI, and the heterogeneity of clinical presentation.^{12,16} Furthermore, there is currently limited evidence to support pharmacologic treatment of NPD following TBI.^{12,17,18} Unknown efficacy, concern about vulnerability of individuals with TBI to adverse events such as seizures, possible side-effects from medications, and possible drug-drug interactions may result in reluctance to prescribe treatment for NPD following TBI.^{18–22}

Few studies have assessed whether individuals with TBI are less likely to receive treatment for NPD. Our recent work conducted among Medicare beneficiaries hospitalized with TBI suggests that they are.^{23,24} Following hospitalization for TBI, Medicare beneficiaries with incident depression were less likely to receive antidepressants compared to similar Medicare beneficiaries without TBI.²³ Similarly, we observed that Medicare beneficiaries diagnosed with anxiety or PTSD following hospitalization for TBI were less likely to receive indicated pharmacological treatment.²⁴ While these studies point to a disparity in receipt of treatment, they tell us little about why the disparity exists. To better understand the experiences of patients with TBI NPD and the healthcare providers who treat them, we conducted a qualitative study. The objective of this study was to explore perceptions of barriers and facilitators to the diagnosis and receipt of treatment for TBI NPD.

Methods

We conducted ten structured interviews with health care providers to gather information on experiences with the diagnosis and treatment of NPD following TBI. Participants included three neuropsychiatrists, a psychiatric nurse practitioner, two psychotherapists, a neurologist, an emergency department physician, an occupational therapist and a speech pathologist. Care settings comprised a clinic specializing in the treatment of psychiatric disorders following brain injury, an emergency department at a large academic hospital, and a state designated primary adult resource trauma center. The interviews were conducted by phone by a single trained interviewer (JSA) between November, 2015 and February, 2016 and lasted between 40 and 50 minutes. Participants were recruited from the Brain Injury Clinic

at Johns Hopkins Bayview Medical Center, the University of Maryland Medical Center, and the R Adams Cowley Shock Trauma Center directly through email or phone and compensated \$100 for their time.

We also conducted four focus groups with individuals with TBI who had experienced/ experiencing NPD and their caregivers. The focus groups were held between March, 2016 and August, 2016 and lasted 90 minutes. Twenty-three individuals participated in the focus groups, of whom 5 (22%) were caregivers. Time since TBI ranged from 18 months to fifteen years. Individuals with TBI were predominantly men (83%) and caregivers were predominantly women (60%). Levels of TBI severity ranged from mild (loss of consciousness less than 30 minutes) to severe (coma). Participants were recruited using flyers and direct mail from the Brain Injury Clinic at Johns Hopkins and the R Adam Cowley Shock Trauma Center and compensated \$50 for their time. JSA moderated all groups with co-moderators LMO and KAM.

Topic guides for the interviews and focus groups were guided by prior literature, clinical experience, and the goals of the project and focused on the three most common TBI NPD: depression, anxiety, and post-traumatic stress disorder (PTSD).⁶⁻⁸ After obtaining informed consent, the interviews/focus groups were audio-recorded and transcribed verbatim. Three members of the study team performed a conventional content analysis on four of the interview transcripts to create an initial coding scheme that was later refined through an iterative process that included the focus group transcripts.²⁵ The remaining transcripts were each coded by two members of the study team to ensure consistency with coding. We used NVivo 11 (QRS International) for coding and later to group text associated with different codes. Following this process, we solicited feedback from our stakeholder advisory board comprising two individuals with TBI, one caregiver, a neuropsychiatrist, and a state-level TBI advocate to inform identification of major themes.

This study was approved by the Institutional Review Board of the University of Maryland, Baltimore (protocol number HP-00065669) and all study participants gave informed consent.

Results

There were differences in the most commonly identified concepts associated with diagnosis and treatment of TBI NPD between the interviews and focus groups. Among the providers, provider type (psychiatrist vs. emergency room physician, for example), access to care (specifically insurance), patient education on TBI NPD, physician referral network, time since TBI, provider education on TBI NPD, cognition level of patient, TBI severity, care setting (emergency department, inpatient, outpatient), diagnosis of TBI NPD, level of caregiver support, and screening for NPS and were most often coded. Among the patients and caregivers, ability to adapt to life after TBI, patient education, access (insurance), self-awareness of TBI NPD, provider type, care seeking behavior, time since TBI, caregiver support, treatment of NPS, and recognition of NPD (by caregivers or friends) were most commonly coded. Patient education, access (insurance), provider type, time since TBI, caregiver support, and recognition or screening for TBI NPD were frequently coded in both

the interviews and focus groups. Using an iterative process and with help from our stakeholder advisory board, we classified identified concepts into the major themes of education, access to care, and support. (Figure) Diagnosis of TBI NPD mediated the effect of factors falling under these themes on treatment of TBI NPD.

Education

Patient, provider, and caregiver lack of education about TBI NPD was a barrier to diagnosis and treatment. Focus group participants consistently reported that they were not told about the risk of TBI NPD, “Nobody said anything about post concussive symptoms, or any of these symptoms, depression, insomnia”. Participants attributed significant delays between symptom onset and recognition that the NPD were related to the TBI to lack of education, “It had been over two years since the accident and I saw a thing about this traumatic brain injury clinic. I saw all the symptoms of TBI, what they were on the website, there were like eight listed and I had seven that just matched them perfectly.”

Providers agreed that patients with TBI were not aware of their risk of NPD. While most thought that patients should receive education about TBI NPD, there was less agreement on who should discuss TBI NPD with the patient and when. Some thought “it should be the responsibility of either the clinicians at the hospitals or the primary care physicians” while others suggested that “every provider that they encounter should be informing them that there is a chance that they might have a psychiatric disturbance.”

Provider education on TBI NPD was identified by interview participants as critical to receiving a diagnosis and/or treatment for TBI NPD. Lack of experience with TBI NPD may result in reluctance to diagnosis, “psychiatrists, neurologists, primary care doctors who don’t see it very often have a hard time making a clear cut diagnosis”, which delays treatment. This could be due lack of recognition that “having a traumatic brain injury does change the way that the psychiatric illness is presenting.” Provider education impacts screening for and decisions to treat NPD; “the non-psychiatric providers ... may not feel comfortable because they do not understand the psychiatric pharmacotherapy and even the providers who do have psychiatric expertise may feel uncomfortable and not familiar with medications related to TBI.”

Interview and focus group participants acknowledged that caregivers often don’t know what to expect post-TBI; “Sometimes you will have families call and say, why can’t this person just snap out of it, you know this brain injury happened so long ago, not realizing that the depression is the symptom of the brain injury.” One focus group participant noted; “there’s kind of a disconnect where they have expectations that you can’t meet because you’re not that person or maybe they’re frustrated because you forgot again.”

Some health care providers suggested that education about TBI should be extended to the community; “those who come in contact with people who have brain injuries. The more education they have about where to steer this person the better”. Focus group participants expressed frustration at the lack of understanding in the community that, “I may look normal on the outside, but I’m not the same person on the inside.” Finally, education of employers may be needed; “there needs to be some sort of education so that employers that are able to

understand the impact of a TBI on an employee”, particularly if that person is to remain employed.

Access to Care

Access to care, comprising health insurance, income, transportation, and availability of providers was identified by all participants as a barrier to receiving a diagnosis and treatment for TBI NPD. Income determines a person’s pre-TBI insurance coverage and vehicle ownership. Post-TBI, income determines ability to pay for office visits, medications, and transportation, which in turn influences care-seeking behavior. Common to all persons who seek mental health treatment, poor insurance coverage for mental health care and finding a provider that accepts a particular insurance are challenges.²⁶

Individuals with TBI and health care providers identified insurance as the most important barrier to accessing care. Focus group participants often had to go through workers’ compensation which was described as a difficult process; “It’s a battle with workmen’s comp. I have to go see their psychiatrist on a regular basis and I always come out, you know, from them that there’s nothing wrong with me and that this is all hyperbole and malingering.” Providers also noted; “Having programs like Workmen’s Compensation can make it very difficult, not always but sometimes.”

Many individuals with TBI lose income because they are unable to resume their previous job; “I was a tractor trailer driver. Well I could never drive again, so there goes my tractor trailer license because I have seizures.” In addition to job loss, patients with TBI often incur medical debt as a result of their injuries. Application for disability status often takes a long time and leads to more debt; “I have had patients who had to wait years to get their disability status okayed and gone through numerous appeals, so the financial burden on people that have had a brain injury can be huge.” This affects their ability to pay for mental health visits as well as out of pocket expenses, particularly among those with poorer insurance coverage.

Individuals with TBI may no longer be able to drive, “I took myself off the road because I couldn’t remember to check the traffic lights” and may also have difficulties navigating the public transportation system due to physical or cognitive deficits. “Just coming in (for treatment) is sometimes very difficult, especially if they rely on public transportation or other people to get them to the appointments” noted one health care provider while a person with TBI added, “What do you do, where do you go, who do you see? I couldn’t drive.”

Finally, long waiting times for appointments with neuropsychiatrists who specialize in the treatment of TBI NPD are common. There are few providers in this specialty and some focus group participants reported travelling an hour and waiting months for an appointment.

Support

Health care providers viewed positive and engaged caregiver support as critical to the appropriate and timely diagnosis and treatment of TBI NPD; “if they don’t have close family or friends who’ve known them through the course of illness, that is a barrier trying to get an accurate diagnosis.” Another participant noted; “Often times, I see that if a patient has a strong support system and an advocate, they pursue treatment and follow up as

recommended.” Caregivers can provide pre-TBI historical information, transport to appointments, organization of the daily schedule, and help with medication adherence.

Nonetheless, living with and providing support to a person with TBI is challenging; “being angry all the time and my wife just couldn’t get over the fact that oh you’re angry all the time. I was like...I didn’t know how else to be.” Lack of knowledge about TBI can result in negative family interactions, “I can do a lot of things that I couldn’t in the beginning. But what you’re not getting is I’m never going to be what I used to be, and I’ve told you I don’t know how many times, but you don’t get it.” Family members and caregivers may not understand how TBI “affects their ability to function, and so family members try a lot of behavior management; trying to punish them for not doing what they feel that they should be able to do.”

Diagnosis of TBI NPD

Diagnosis and treatment of TBI NPD starts with recognition and screening, yet providers may not know that an individual with psychological complaints had a head injury. Mental health care providers admitted that asking about history of TBI was not part of routine screening prior to working in a brain injury setting. Lack of screening for NPD may be a barrier; “I think if primary care doctors and other physicians or providers screened for symptoms, they would be more likely to refer to a psychiatrist or neuropsychiatrist.” However, there are currently no evidence-based screening tools for TBI NPD.

Even with screening, diagnosis of NPD is challenging following TBI. Under-diagnosis is common because symptoms differ; “even if people report various psychiatric symptoms after TBI to their primary care doctor or neurologist, it may not get recognized as a specific disorder because the symptoms don’t necessarily match regular psychiatric disorders.” Misdiagnosis can lead to improper prescribing, “People with these severe motivational syndromes sometimes appear depressed. They get put on antidepressants when antidepressants won’t work and may even make it worse.” Furthermore, treatment of TBI NPD is complicated by polypharmacy; “you have to be careful about mixing medications. They are frequently on a number of other medications to treat problems related to or preceding the brain injury.”

Discussion

TBI is often called a ‘silent epidemic’ because it affects so many but is largely unrecognized.²⁷ Despite high rates of NPD following TBI, evidence-based guidelines for diagnosis and treatment are lacking, contributing to disparities in treatment.^{12,17,18,23,24} This study engaged patients, caregivers, and health care providers to identify barriers and facilitators to the diagnosis and treatment of TBI NPD. The issue is complex, but we have separated identified concepts into three actionable themes: education, access, and support. These three concepts impact treatment of TBI NPD through diagnosis of NPD.

Education of health care providers, patients, and the community on TBI NPD is critical. The majority of individuals with TBI and their caregivers were not educated about possible emotional, cognitive and/or behavioral changes following TBI. This lack of education leads

to delays in diagnosis and treatment and results in feelings of hopelessness and frustration for patients and caregivers. Providing information on NPD risk and symptoms to watch for could improve diagnosis and treatment. Including evidence-based information on TBI NPD in the automated discharge instructions received from the emergency department or hospital could help to inform patients, but education for providers in the form of seminars and workshops is also needed to heighten awareness and increase screening and referral. Education of the community could be pursued through community engagement programs already in existence at urban, academic hospitals such as ours and through local events hosted by the Brain Injury Association.

TBI NPD diagnosis and treatment requires access to medical care, which is driven primarily by insurance coverage, and to a lesser extent by transportation. Uninsured individuals and those who need to apply for social security disability insurance or even workers' compensation could be guided in the process of applying for insurance by a care coordinator or health system navigator in the trauma center, emergency department, or possibly in an outreach center. Continued work to highlight the risks of chronic physical and psychological problems following TBI and the benefits of treatment will inform policy changes to broaden coverage of physical and psychological sequelae of TBI. Individuals with TBI who need transportation could be directed toward volunteer services that provide transportation to appointments for home-bound neighbors.

An individual's social support is dependent largely on pre-TBI support and functioning. Education about TBI NPD would help caregivers and the community provide support by setting expectations about post-TBI functioning and recovery. Furthermore, support groups for caregivers of persons with TBI would provide a means to share experiences and gain insight into strategies that work. Some health care providers suggested that social support in the form of support groups or even a community center could augment or replace family support and provide individuals with TBI information on available resources. At the health care system level, follow-up calls from a nurse navigator health care provider to schedule appointment and assess needs could improve care. Systems already in place to reduce hospital readmissions, such as follow-up calls and clear patient education about TBI NPD and resources in the area, could be effective for individuals with TBI.²⁸

Limitations

This study was limited by our ability to recruit individuals with TBI NPD, despite help from TBI providers and advocates. Many factors may have played a role, including the NPD itself, lack of transportation and cognition. Consequently, most focus group participants were affiliated with a clinic specializing in the treatment of TBI NPD and may not represent all people with TBI. Nonetheless, the concepts identified in the focus groups were similar to those identified by providers, supporting generalizability. We were initially interested in separating the focus groups by severity of head injury, but learned that patients often were not aware of the severity of their TBI. This in combination with slow recruitment led to mixed compositions of the individuals. Interestingly, their experiences often overlapped, suggesting that the severity of TBI plays a limited role in diagnosis and treatment of TBI NPD. Although our focus was depression, anxiety, and PTSD following TBI, focus group

participants did not differentiate between sequelae of TBI, discussing anger, insomnia, cognition, or job loss in the same sentence as depression or anxiety. This provided insight into another possible barrier to diagnosis and treatment of TBI NPD: they form only a part of the sequelae that persons with TBI experience. Improving the quality of care for TBI NPD may require a comprehensive approach.

Conclusions

This study explored patient, caregiver and health care provider – identified barriers and facilitators to the diagnosis and receipt of treatment for TBI NPD. Barriers included poor provider education on TBI NPD and limited access to care due to lack of insurance, transportation, and income. Facilitators included patient education on TBI NPD and strong caregiver support. We also have described several strategies to improve the quality of care for TBI NPD. Future studies should develop and pilot interventions aimed at quality of care that address the identified barriers and facilitators.

Conflicts of Interest and Source of Funding:

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Abbreviation List:

NPD	neuropsychiatric disturbance
TBI	traumatic brain injury

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Figure.

Factors Contributing to Diagnosis and Treatment of Psychiatric Disturbances following TBI