A qualitative study of providers’ decision-making for cases involving neurobehavioral issues

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Abstract: Across the continuum of care, providers representing multiple professions (i.e., rehabilitation, medical, mental health) influence post-acute care planning for persons with brain injury, yet insufficient evidence informs how decisions are made. The need to understand provider decision-making is paramount, particularly for a person with brain injury whose sequelae necessitates integrated, interprofessional care. Using vignettes drawn from authentic scenarios, this qualitative study investigated case management decisions made by providers serving individuals with varying neurobehavioral needs. Responses to three open-ended scenarios concerning neurobehavioral service provision were collected, coded, and analyzed in accordance with rigorous qualitative conventions. Participants (n = 84) represented an array of organizations serving persons with brain injury. The results revealed two courses of action: dominant and supporting. Although most respondents indicated integrated care as the ideal pathway, their concretized recommendations yielded actions focused on a single referral within the traditional medical model rather than an interdisciplinary approach. While integrated, interprofessional treatment and working across systems are considered optimal, this study suggests that in the current practice

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Dr. Cynthia O’Donoghue and Dr. Cara Meixner, both professors at James Madison University, are co-founders and primary investigators of the Brain Injury Research Team (BIRT). BIRT is committed to expanding knowledge of brain injury to improve the outcomes of survivors, their families, and their communities. The team employs rigorous methods, both quantitative and qualitative, to investigate issues surrounding living with a brain injury including, but not limited to access to care, rehabilitation, mental health, caregiving, and quality of life. BIRT team members believe that data-driven findings can positively influence legislation, driving policy and person-centered practices that better the lives for all. Commensurate with these aims is the current study, which looks critically and systematically at provider decision-making around complex neurobehavioral cases.

PUBLIC INTEREST STATEMENT
Recovery from brain injury, particularly those that are severe, may require years of intervention ranging from cognitive, physical, occupational, and speech therapies to ongoing surgeries, pharmacological management, supportive living, and adult day care. Many survivors live with lingering deficits, among them neurobehavioral (i.e., influencing or thwarting emotion, behavior, and learning). Within the literature, however, limited evidence informs how providers across the continuum of care make decisions—and whether decisions entail interprofessional collaboration. This qualitative study informs this void in the research, highlighting the challenges affiliated with complex case management decisions, particularly for individuals receiving post-acute care. Although participants noted the merit of interprofessional treatment teams and working across systems as optimal, most defaulted to a less interdisciplinary approach (i.e., a single provider medical model). This highlights the conflicts that providers navigate and the need for resources that promote an integrated, interdisciplinary team approach.
such a model is still evolving. This duel between “ideal” and “actual” highlights the need for further study, as well as resources to support best practices in rehabilitation and recovery.

Subjects: Rehabilitation Medicine; Disability; Neurological Rehabilitation

Keywords: brain injury; neurobehavioral; interprofessional team; rehabilitation; community-based care

1. Introduction

Acquired Brain Injury (BI) is a neurological diagnosis that often manifests with a broad array of deficits, typically necessitating emergent hospitalization followed by acute rehabilitative care and a post-acute rehabilitation phase focused on return to the community. Many persons post BI require case management and support services extending well beyond the initial phases of recovery (Kenzie et al., 2017; Mazaux & Richer, 1998). Further, survivors endure an intersected, non-linear recovery pathway; success hinges, especially for persons with neurobehavioral presentations, on the guidance of multiple professionals (i.e., rehabilitation, medical, mental health) in the context of an interdisciplinary team. Having multiple service providers contributing their professional perspectives and recommendations to a person’s rehabilitation plan is paramount, as it has the potential to influence the type, frequency, and manner of therapeutic care provided. Given extant barriers, however, providers may not always work interdependently.

Unfortunately, limited empirical evidence informs how teams make decisions and how individuals progress through a complex continuum of care following brain injury. This issue becomes even more pronounced when searching for information on how individuals are referred for and managed in the post-acute, community-based care setting. This qualitative study makes a unique contribution to the literature; its objective is to investigate the case management decisions made by providers, representing various agencies and organizations working with persons with BI involving neurobehavioral issues. The outcomes of this study will inform how decision makers’ perspectives influence a system-wide continuum of care for persons with neurobehavioral issues.

A brief review of the literature precedes an orientation to the study’s methodology, which employed an innovative qualitative approach designed to bring to the surface providers’ decisions regarding authentic neurobehavioral scenarios. The method, drawn from participant reflections on three vignettes, is detailed. Procedures for coding, analysis, and integration are presented. From there, results are arrayed as core and subordinate themes. Recommendations and implications for practice are discussed, forecasted, and advised.

2. Literature

Stroke and traumatic brain injuries comprise the majority of acquired brain injuries. Recovery from BI, particularly severe injuries, may require years of intervention, and still, many survivors report living with lingering deficits (Jamora & Ruff, 2012; Payne et al., 2018). Brain injury is now recognized as a chronic health condition rather than an isolated medical event (Mosel & DeWitt, 2010; Pöttker et al., 2017). The well-publicized research regarding the long-term, cumulative effects of repeated concussive injuries linked to Chronic Traumatic Encephalopathy (CTE) in football players illustrates this phenomenon (Mez et al., 2017; Solomon, 2018). However, chronic effects of brain injury are not limited to repetitive, sports-related head injuries. Persons with isolated traumatic head injuries in childhood or early adulthood, for example, are at increased risk for neurophysiological alterations in normal aging, producing a potential neurogenerative disease-accelerating process (Griesbach et al., 2018; Wilson et al., 2017). A health policy study in Massachusetts regarding the long-term implications following BI found, “In the chronic phase of acquired brain injury from any cause, lifelong disabilities may affect the ability to work, perform activities of daily living (dressing, paying bills), participate in community life, and/or fulfill a family role” (Lorenz & Katz, 2015).
The constellation of challenges following BI often results in neurobehavioral (NB) issues, with neurobehavioral defined as the way that the brain influences emotion, behavior, or learning (Centers for Disease Control and Prevention, 2016). NB concerns are typically complex, distorting many aspects of a person's holistic well-being—cognitive, behavioral, physical, and psychiatric (Dillahunt-Aspillaga & Powell-Cope, 2018). Figure 1 displays these NB concerns and associated symptoms (O'Donoghue et al., 2015). Though the figure displays discrete quadrants, these should be understood as both related and intersected. The potential areas of compromise following BI as evidenced in the figure provide a picture supporting the diversity of professionals needed to optimize the recovery process.

Ideally, an interdisciplinary team of professionals develops and executes an individualized treatment program drawing on the expertise of rehabilitation nursing, physical therapy, occupational therapy, speech-language pathology, physical medicine, neuropsychology, and psychiatry (Traumatic brain injury: hope through research [PDF], 2015). In the late 1990s, a panel of experts working with the National Institutes of Health (NIH) recommended that a person, post brain injury, participates in a program based on identified strengths and weaknesses, with the recognition that this plan will require adjustments in rehabilitation services to address the person's evolving needs over time (NIH Consensus Development Program Archive, 1998). Relatedly, a seminal paper by Mazaux and Richer (Mazaux & Richer, 1998) stressed the importance of a rehabilitative team approach premised on providing “assistance and comfort to the patient and the family … [and] flexible enough to continue even if the patient’s situation is changing”. In other words, consideration of caregiver needs may be tantamount to assuring support for survivors of brain injury.

Persistent NB challenges following BI alter functional abilities and independence, often making survivors reliant on their caregivers, as well as service providers and social systems (i.e., Social Security, Medicare and Medicaid) for support. Research confirms that persons with NB issues following BI are more likely to achieve optimal outcomes (e.g., functional independence) when
treated by an interprofessional team of healthcare providers working across various points of service delivery. Unfortunately, there are numerous barriers to care that hinder optimal recovery, as well as interprofessional collaboration. These include, but are not limited to financial aspects (e.g., insurance coverage), transportation, lack of qualified providers, and chasms in the BI continuum of care (Albrecht et al., 2017; Meixner et al., 2013).

As noted prior, evidence to support providers’ decision-making regarding the continuum of care options is limited. One multi-center study of 504 post-acute BI cases identified through cluster analysis five unique profiles that are purported to inform clinicians’ decisions regarding case management cognitive, emotional, and physical symptoms; personal strengths; physical functioning; environmental supports; and performance validity (Sherer et al., 2017). While this work highlights the variety of life long, persistent issues limiting functional recovery—specifically, the neurobehavioral issues often associated with BI—further investigation of the case management decisions made by providers working with these individuals is warranted.

3. Materials and methods
To meet its identified aims, this qualitative study analyzes the responses to three authentic, open-ended scenarios (refer to Table 1). An online methodology was chosen for its capacity to reach a broad array of geographically diverse participants. Other benefits of online qualitative methodologies are well documented (Bouchard, 2016; Buchanan, 2000), with participants feeling less inhibited and more forthright than they would be in a face-to-face interview. In other words, online anonymity afforded the opportunity to appraise provider decision-making without any fear, on their part, of recourse or judgment.

Figure 2 presents a flowchart articulating the research methodology and approach. These scenarios were nested within a larger study, focused within a mid-Atlantic state, to investigate systematic needs concerning neurobehavioral service provision. The study was approved for human subjects by the Institutional Review Boards affiliated with the researchers’ academic institution and the state agency providing fiscal support for the investigation. All participants provided written consent to engage in the study.

3.1. Participants
Participants in this study were professionals identified as persons who could respond on behalf of an organization or agency serving persons with brain injury in a mid-Atlantic state in the United States. Included were 190 publicly listed providers, organizations, or agencies. Given significant overlap between the documents used to compile the participant list, reasonable efforts were made to send the survey to one individual per entity, so as to eliminate duplicative responses. Eighty-four (n = 84) individuals, each representing an agency or organization partook in the study, resulting in a 44% completion rate.

| Table 1. Open-ended response prompts |
|-------------------------------------|
| **Scenarios:**                     |
| You currently serve a 24-year-old individual living with their family in the Commonwealth of Virginia who attends a clubhouse/day program during the week. Recently, this individual is exhibiting escalating agitation, aggressiveness, and apathy consistent with a neurobehavioral profile. The day services provider has called to tell you this behavior is now manifesting in yelling and an inability to be consoled. Given this scenario, what do you perceive as the best course of action? |
| You currently serve a 45-year-old individual who sustained an injury to the frontal lobe as a result of a car accident. This individual has completed an inpatient rehabilitation program but continues to exhibit impulsivity and memory loss with intermittent spells of depression. This individual now resides in a group home that accepts their Medicaid coverage. Given this scenario, what do you perceive as the best course of action? |
| A social worker contacts you as a recognized expert on brain injury in the Commonwealth of Virginia. She has an individual with severe neurobehavioral issues; the individual has been accepted and discharged from four nursing homes based on unmanageable behaviors. What suggestion do you have for this individual? |
|-------------------------------------|
Respondents clustered into three core types of agencies representing 80 municipalities across the state: brain injury or disability providers, other public agencies, or other private agencies. At the time of the study, 59% provided services to specific regions or municipalities, whereas 41% provided statewide services. Notably, 51% indicated that their organization offered programs or services specific to individuals with neurobehavioral needs with caseloads ranging from 4 to 1,200 per year or a low average of 158.

3.2. Measures
This study was part of a larger investigation utilizing a web-based needs assessment instrument adapted from the Rutgers Center for State Health Policy (Gadoba et al., 2009). For this sub-study, three scenarios were designed to elicit insight into the courses of action that a provider would take to serve persons with neurobehavioral needs. The scenarios were written by the research team to reflect a constellation of neurobehavioral issues (e.g., mood lability, impulsivity, difficult behavior) present in the rehabilitative, psychological, psychiatric, and mental health literature. To assure clarity, readability, and understandability, the researchers piloted the scenarios to a sample of providers. Please refer to Table 2 for the acquired brain injury and neurobehavioral definitions offered to respondents, which was designed to minimize response error and provide a common understanding of these constructs as they relate to the phenomenon under investigation.

4. Data analysis
To code and analyze the data, the researchers applied a rigorous set of qualitative procedures rooted in a grounded theory approach (Charmaz, 2014). The grounded theory method differs from an a priori coding approach, wherein codes are pre-set (e.g., derived ahead of time from the literature). The benefit of a grounded theory approach is its propensity to delimit researcher bias, as well as any bias derived from existing literature. Procedurally, the data were imported into NVIVO 10, a qualitative software tool, for coding and analysis. First, data were open coded, whereby participant responses were named, line by line, to codes that reflected their meanings. Open coding was performed by scenario, with themes later generated across all three scenarios. That is, as codes accumulated, they were organized by the researchers into themes or categories designed to reflect relative saturation across the responses. Importantly, data were analyzed by three members of the research team (i.e., both co-primary investigators and a graduate assistant) according to a consensus procedure, which assures findings adhere to qualitative trustworthiness criteria, such as credibility and confirmability (Creswell, 2017; Lincoln & Guba, 1985).

5. Results
Data were coded and analyzed into dominant courses of action (i.e., primary courses of decision-making articulated by respondents), subordinate courses of action (i.e., secondary, supplemental,
Table 2. Operational definitions for providers responding to the case scenarios

| Term                                      | Definition                                                                                                                                                                                                                                                                                                                                 |
|-------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Acquired brain injury (ABI)               | Acquired brain injury refers to brain trauma that occurs after birth. ABI does not include diseases that are a result of a progressive loss of cells in the nervous system such as Alzheimer’s, Parkinson’s, and ALS. Two of the leading causes of acquired brain injury are stroke and trauma brain injury (TBI). However, acquired brain injury can also be caused by oxygen deficiency, infectious diseases (e.g., meningitis), toxic chemical exposure, electrical shock, and brain tumors (O’Donoghue et al., 2015). Acquired brain injury is an inclusive term that refers to any damage to the brain that is not of a developmental or neurodegenerative cause. |
| Neurobehavioral                           | Neurobehavioral refers to the way the brain affects emotion, behavior, or learning (Centers for Disease Control and Prevention, 2016)                                                                                                                                                                                                       |
| Neurobehavioral needs                     | Neurobehavioral needs refer to the compromising cognitive, behavioral, and/or social changes that result from an acquired brain injury (ABI). Although these needs and their duration vary depending on the severity of the injury, individuals with both mild and severe brain trauma may experience changes in their personalities, find problem solving difficult, experience a lack of motivation, or act impulsively. Neurobehavioral needs for individuals with persistent neurobehavioral issues often stem from compromised functional abilities that limit an individual’s ability to engage in professional, social, and educational activities. Additionally, co-morbid psychiatric and mental health diagnoses are not uncommon while persistent neurological disabilities may lead to under-employment and increased rates of government financial assistance and incarceration (Baddeley, 1986, DeGuse et al., 2008, Evans, 2001, Johnstone et al., 2003, Wood, 2001, Zasler et al., 2013). |

or less prominent courses of decision-making), and concrete outcomes affiliated with such courses of action. The data also indicated primary support persons (i.e., providers) named by survey respondents in their open-ended narratives.

5.1. Dominant course of action: referral and assessment
Participants described their dominant course of action for each of the three neurobehavioral scenarios. In most instances, a singular course of action was identified, though many respondents idealized an interdisciplinary, coordinated, and/or team-centric approach. Four primary themes, clustered around the organizing concept (i.e., idea cluster) of referral and assessment, are explored below. Each of these themes was coded as primary for two reasons: the theme was redundant across participants’ overall responses and evident across all three of the neurobehavioral scenarios.

The first theme, interdisciplinary, coordinated, and/or team-centric approach, pointed to the importance of a course of action featuring integration within and across a continuum of care. For one respondent, this entailed providing “a combination of guidance and monitoring services from specific health, psychiatric/neuropsychological services to community reentry ... through a well-organized case management system.” Augmenting this statement was the idea of “[having] a meeting with all those involved in this individual’s case, i.e., individual, family, caregivers, case manager, doctors, counselors, etc., to put a plan of action together.”
The second and third themes regarded referral and assessment by a neuropsychologist or neuropsychiatrist and referral and assessment by a physician. Differentiating these two is a focus on triage. Whereas some respondents recommend that a specialist direct the primary course of action (e.g., “Depending on [neuropsychological] findings, you can proceed with appropriate forms of help and intervention.”), others identified the primary care physician (PCP) for this role (e.g., “This individual would need to be evaluated medically [by the PCP]” and “I would suggest they consult with the individual’s PCP [first]”). As evidenced by a fourth theme, referral and assessment-general, many participants named the importance of thorough assessment, though the provider type was unspecified (e.g., “A thorough assessment of the individual by a trained professional is needed to see what the exact needs are.”).

Secondary to the four primary themes noted above were four additional themes—still highly evident in the coding matrix and in support of a course of action focused on referral and assessment, but less dense. These included referral to a brain injury provider for case management (e.g., “Refer client for community-based case management support to help coordinate the services needed.”), consultation with client and/or family (e.g., “I would engage the individual as an active participant,” and “My suggestion ... is to meet with the individual’s family.”), consultation with mental health professional or agency (e.g., “I’d consider referral to [community mental health] services, to see if residential services might be obtained.”), and referral and assessment by a behavior management specialist (e.g., “I would ask what positive behavioral supports had been used and if there was a behavior specialist involved. If not, I would recommend a consultation.”).

Although the data analysis revealed primary and secondary themes around dominant courses of action, there were additional courses of action. Though each of these was reported, respectively, by less than 10% of the respondents, they are worthy of notation as they highlight the wide variety of actions providers might take: consideration of move to residential setting; cognitive testing and/or therapy; referral to advocate-ombudsperson; consideration of club, day, or outpatient program; stabilize at emergency room; and evaluation of home situation.

5.2. Supporting courses of action
In some cases, participants described a supporting or complementary course of action qualified by tentative terms such as “maybe” or “perhaps.” Reported here are four themes evident within and across participants’ responses to the three neurobehavioral scenarios. The first theme pointed to education and training for staff and/or family. Such training might focus, for instance, “on how best to manage aggressive, emotional behaviors” or “developing antecedent strategies or other interventions.” Behavioral management also complemented participants’ responses (e.g., “Once any outstanding medical/medication issues are addressed, this should be followed by a comprehensive behavior assessment by a licensed clinical psychologist ... or similar expert.”). Finally, some participants mentioned neuropsychological evaluation and medical evaluation to augment primary courses of action (e.g., “A medical evaluation to rule out potential medical, illness, or medication issue could be needed.”).

5.3. Outcomes of course of action
Though the open-ended scenario prompt asked participants to designate a course of action, many participants did not indicate a process—instead, they designated a concrete outcome. An organizing concept arose around the notion of review and adjust medications, pursuant to referral and assessment by a physician, neuropsychiatrist, or neurologist. Specific comments included, “Most individuals will never recover from this type of injury, but they can be controlled with medications and therapy,” and “See if medication would or could be helpful in controlling the behaviors.” This theme surrounding medication was seconded by behavioral modification—such as de-escalation and positive behavior supports. One respondent pointed to beginning “a plan of behavioral intervention to remediate behavior through positive outcomes and rewards.” Another noted that a “behavior specialist can work with the individual and his/her family, as well as the staff
and residents of the program.” Additional themes regarding residential admission and placement and enactment of a person-centered care plan were specified by a smaller number of respondents.

5.4. Support persons named

Upon analysis of the results reported on courses of action, the research team recognized the wide array of actors and agents named by respondents. To that end, simple frequencies were generated in order to better understand the individuals to whom respondents turn when considering such courses of action. In order of the most to least prominent, these were physician (general), neuropsychologist or behavioral psychologist, neuropsychiatrist or psychiatrist, mental health professional, family, case manager, and behavioral analyst or specialist.

6. Limitations

While this study achieves a desirable sample size with adequate representation across provider groups, the results cannot be said to be generalizable but rather, transferable (Creswell, 2017). In other words, the results cannot be said to represent the perspectives of all providers within a given population. Rather, the reader is made aware of ways in which providers may make decisions, or are most likely to respond, to neurobehavioral issues encountered by persons with brain injury. Further, the study was limited to a mid-Atlantic state, one that bears a continuum of similarities and differences (ranging from funding models to resources and policies) to other states, regions, or localities.

7. Discussion

The objective of this qualitative study was to investigate case management decisions made by providers serving individuals with varying neurobehavioral needs. This aim was met through the processes of data collection, consensus coding, and thematic analysis. The results revealed two intersected courses of action—dominant and supporting—that signal a concrete penchant for single referral (i.e., to one provider, such as a physician) yet point to the desire for interdisciplinary care. Among the methodological benefits of this nonexperimental approach was its ability to invite insights from an array of providers practicing in authentic, naturalistic settings (versus through a laboratory experiment or a trial). As such, providers’ lived experiences among persons with brain injury—in the greater context of funding issues, public policy, and other barriers—richly informs the themes that emerged.

Participants described dominant and supporting courses of action to respond to each of the case scenarios, with results yielding singular, referral- or assessment-based solutions. Though a majority of participants suggested idealized or hoped-for interdisciplinary, coordinated, or team-based approaches, the default response surrounded a medical orientation—referral to a neuropsychiatrist, neuropsychologist, general physician, or another provider. Among the dominant courses of action identified by respondents, less common were those that entailed consultation with mental health professionals, let alone the client or family member/caregiver. Altogether absent was the identification of other rehabilitation professionals (e.g., OTs, PTs, SLPs) as prospective agents of support. This outcome is unanticipated given the vast array of participating provider typologies, especially those whose clients have neurobehavioral issues. However, this finding lends credence to previous studies where patients and carers report a lack of integrated care resulting in service fragmentation, particularly in the post-acute, community-based setting (Abrahamson et al., 2017; Schumacher et al., 2017).

Results revealed most courses of action identified by respondents were singular, suggesting that one approach could remediate the concerns evident in the cases. Some participants hinted at supporting courses of action, like education and training for the family, behavioral management, and/or neuropsychological or medical evaluation. However, these courses of action were phrased tentatively by the study’s participants (i.e., “maybe ...” or “perhaps ...”); the dominant courses of action, on the other hand, were written in active voice, with definitive and focused language (e.g.,
“I would … “My suggestion is ….”). Though the scenario prompt asked participants to identify a course of action (i.e., process), many participants designated concrete, focused outcomes: mediate the patient, modify behavior, admit to a residential facility, or—more proactively—develop a person-centered care plan.

The results of this research parallel earlier findings concerning barriers to accessing services for persons with brain injury (Meixner et al., 2013); given financial strains and resource-related concerns, many systems of care are siloed, lacking integration or clear recovery pathways. In spite of a growing body of literature documenting the merits of integrated care, many practices continue to default to a model within which the perspectives of rehabilitation professionals, mental health professionals, caregivers, and survivors are subordinate. This investigation well demonstrates the current duel between ideal and reality as providers seek to integrate care across professions and agencies. Yet brain injury is not an event—it is a process (Masel & DeWitt, 2010) necessitating long-term, person-centered planning that is integrated across a continuum of care. There is much literature on the various clinical aspects involved with brain injury rehabilitation and recovery, but there is an absence of empirical evidence guiding integrated, interprofessional practices (Pal, 2020). Additional research to affirm best practices and alleviate the systemic gaps in care for these individuals is merited. Further, provider education and training will prove paramount as next steps to holistic care if we are to influence policy to meet the complex needs of individuals with brain injury, especially those with neurobehavioral issues.

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