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Patients' and caregivers' perspectives on healthcare navigation in Central Indiana, USA after brain injury

Johanne Eliacin[1,2,3,4] 🄳 | Sarah K. Fortney[2] | Nicholas A. Rattray[1,5] | Jacob Kean[6,7]

[1]Richard L. Roudebush Department of Veterans Affairs Medical Center, Center for Health Information and Communication, Health Services Research and Development, Indianapolis, IN, USA

[2]Departments of Psychology, Indiana University Purdue University at Indianapolis, Indianapolis, IN, USA

[3]Regenstrief Institute, Inc. Indianapolis, IN, USA

[4]Act Center of Indiana, Indianapolis, IN, USA

[5]Department of Anthropology, Indiana University Purdue University at Indianapolis, Indianapolis, IN, USA

[6]Informatics, Decision-Enhancement and Analytic Sciences Center, Health Services Research and Development, VA Salt Lake City Health Care System, Salt Lake City, UT, USA

[7]Department of Population Health Sciences and Department of Communication Sciences and Disorders, University of Utah School of Medicine, Salt Lake City, UT, USA

Correspondence
Johanne Eliacin, Center for Health Information and Communication, Department of Veterans Affairs, Veterans Health Administration, CIN 13-416, Richard L. Roudebush VA Medical Center, 1481 W 10th St, 11H, Indianapolis, IN 46202, USA.
Email: jeliacin@iupui.edu

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Abstract

Little research has documented the experiences of patients with traumatic brain injury (TBI) and their caregivers in navigating health systems for TBI care. In this qualitative study, we conducted semi-structured interviews with 62 participants (34 patients with moderate or severe TBI and 28 caregivers) from Central Indiana. Data were collected from January to September 2016 and analysed using a constructivist grounded theory approach. Participants discussed three significant challenges about navigating health services for TBI care: lack of support for care navigation, financial barriers, and communication barriers. Participants described how navigating out-patient healthcare services for TBI remains complex and emphasised the need for ongoing care navigation support throughout the care continuum. They detailed the long-term financial burden of TBI including high treatment costs, limited insurance coverage, and the emotional toll that financial stress has on their ability to navigate healthcare services for ongoing TBI-related needs. They also discussed how ineffective patient–provider communication and lack of reliable, timely and comprehensive health information about TBI limited their engagement in and navigation of TBI health services. Findings suggest that persons with TBI and their caregivers need ongoing support to manage the long-term impacts of TBI. Efforts to provide care coordination and navigation to patients with TBI and their families are urgently needed to facilitate greater access to care, effective healthcare navigation and improved health outcomes.

KEYWORDS
health services, healthcare navigation, patient navigation, qualitative research, rehabilitation, traumatic brain injury

1 | INTRODUCTION

In recent years, health services and rehabilitation research have increasingly turned attention to understanding how patients navigate the growing complexity of health systems, which often requires adequate health literacy, effective health communication, illness management skills and support to overcome health system barriers (Fouad et al., 2016; Gimpel et al., 2010). Emerging healthcare navigation studies demonstrate that despite available treatment guidelines, patients with chronic conditions, such as diabetes and cancer, often do not receive recommended care or achieve their healthcare goals (Ali-Faisal et al., 2017; Hossain et al., 2013; Shockney, 2010). These challenges may involve a combination of patient-, provider- and system-level barriers such as financial constraints and unawareness of available resources (Decker, 2007; Koch et al., 2015; Protheroe et al., 2009; Shaw et al., 2009). Understanding how these challenges

unfold over time for patients with chronic conditions is critical for creating effective healthcare practice guidelines and policies to provide timely, effective and person-centred care (Hossain et al., 2013; Shockney, 2010). This is even more essential in health conditions such as traumatic brain injury (TBI), which has no clear treatment guidelines for post-hospitalisation or long-term care (Masel & DeWitt, 2010).

TBI, caused by a bump, blow, jolt or a penetrating head injury, disrupts normal brain function. It is a major public health problem that affects millions of individuals and causes over 56,000 deaths every year (CDC, 2019; Pundlik et al., 2020). TBI severity ranges from mild (brief change in mental status) to severe (long-term health conditions or even life-long disabilities; deGuise, 2008; Pugh et al., 2016). In recent years, TBI has been reconceptualised from a single life event to a chronic health condition requiring ongoing assessment and care (Andelic et al., 2016; Reis et al., 2015; Rotondi et al., 2007; Stocchetti & Zanier, 2016). This shift has significant policy, financial and healthcare implications for patients and their families as they seek and utilise health services for TBI. Patients with moderate to severe TBI often have higher healthcare utilisation due to comorbidities and persistent sequelae from their injury (Dismuke et al., 2015; Rockhill et al., 2012). They may also require costly specialty and extended outpatient care from multiple providers, necessitating effective healthcare navigation (Koch et al., 2015; Leith et al., 2004; Smith & Smith, 2000).

Navigating healthcare systems involves seeking and receiving care, coordinating and paying for care, understanding health information and interacting with providers and staff, all while managing one's illness (Ryvicker, 2018). Research on navigating healthcare for chronic conditions reveals lengthy, stepwise, complex and emotionally burdensome processes (Peel & Harding, 2014). For example, studies on navigating dementia care reported service underutilisation due to lack of knowledge of available services, unmet healthcare needs for patients and caregiver burden, in part due to the mismatch between bureaucratic systems and families' needs (Brodaty et al., 2005; Lloyd & Stirling, 2011). Patients navigating chronic pain care in the Veterans Health Affairs (VHA) emphasised frustration with logistical barriers of VHA paperwork, tensions about treatment options and perceived burden of having to reintroduce themselves constantly to healthcare providers in training (Driscoll et al., 2018).

Studies on patients' experiences with navigating health systems for TBI post-acute care are limited. Existing studies are primarily surveys that identified gaps in healthcare systems, including disparities in access to acute and outpatient health services (Griesbach et al., 2015; Rotondi et al., 2007; Schulz-Heik et al., 2017) and barriers to services for rural patients (Leith et al., 2004; Sample & Langlois, 2005; Solovieva & Walls, 2014). These studies underscored the urgent need to 1) describe the experiences of TBI patients as they navigate different aspects of health systems, and 2) identify health systems' inefficiencies to improve patients' experiences and outcomes.

Yet, less is known about how TBI patients and their caregivers perceive barriers to care and devise strategies to overcome challenges in their everyday lives. This is also important because TBI health services and other resources vary geographically within the U.S. and are influenced by state legislations. For example, the most recent

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What is known about this topic

- Healthcare navigation studies demonstrate that despite available treatment guidelines, patients with chronic conditions often do not receive recommended care or achieve their healthcare goals.
- Understanding how challenges to healthcare navigation unfold overtime is critical for creating effective healthcare and providing effective, person-centred care.

What this paper adds

- Drawing from participant narratives, our findings emphasise the need for care navigation support throughout the TBI care continuum.
- Unavailability of comprehensive and reliable TBI patient education and TBI treatment across the care continuum combined with ineffective patient–provider communication undermine patients' engagement in health services.
- Patient navigation care model could help reduce barriers to healthcare navigation or TBI.

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available epidemiological data indicate that the rate of TBI in Indiana was 16.2 per 100,000 in 2014 (Indiana State Department of Health). In 2020, Indiana has an estimated population of 6.76 million. The care continuum for patients with moderate to severe TBI in Indiana involves acute hospital stay followed usually by short-term rehabilitation care. Once patients are discharged from rehabilitation care into the community, they may follow-up with outpatient care providers and specialists, such as physical therapist, as needed. Patients requiring more intensive outpatient-based care may receive long-term services in nursing homes, or at home- and community-based long-term services, such as through adult day care programs or assisted living facilities. However, for individuals who are unable to pay for healthcare services privately or through their private health insurance company, a TBI waiver is often required to have access to these services. Yet, only 200 slots are available statewide (Brain Injury Fact Sheet: CICOA, 2020). The waiver also uses a very strict definition of TBI that excludes many TBI survivors. While these services are valuable, they are not tailored to the needs of people living with brain injury and there is no specialised brain injury care training required for providers (Brain Injury Fact Sheet: CICOA, 2020).

Given the various types of service pathways to care, the aim of this study was to describe TBI patients' and caregivers' experiences navigating health systems for TBI care after discharge from acute care (inpatient and rehabilitation). Caregivers were included given their crucial roles as decision-makers and support systems for TBI patients, providing a different yet complimentary perspective. Indeed, even individuals who are mostly independent and able to manage their daily care activities, often require family members to assume the role of care provider (Oyesanya, 2019).

2 | METHODS

Our findings are based on qualitative data collected from January to September 2016 from a multi-methods study evaluating TBI health services utilisation in Indiana (Eliacin et al., 2018). Semi-structured qualitative interviews focussed on patients' and caregivers' experiences with navigating health services for TBI care. Interviews were audio-recorded, transcribed verbatim, de-identified and transferred to Atlas.ti for analysis (Muhr, 2012). All participants provided written informed consent prior to being interviewed. Study procedures were approved by the Indiana University Institutional Review Board.

2.1 | Data collection

We recruited a non-probabilistic, purposive sample of participants (Palys, 2008) using several methods, including leaflets, snowball sampling (Bernard, 2011; Kadushin, 1968) and directly contacting TBI patients and their caregivers from an inpatient rehabilitation centre and community support groups. Patient/caregiver dyads were invited to participate in the study. However, we also included patients who did not have a caregiver available to have their perspectives. Patients self-reported demographic characteristics and completed at time of the interview, the Ohio State University Traumatic Brain Injury Identification Method (OSU TBI-ID; Corrigan & Bogner, 2007), a standardised clinical and research tool capturing patients' TBI history and severity. A team of interviewers consisting of two doctoral-level anthropologists and two research assistants conducted the face-to-face interviews, primarily at a local healthcare facility in Indianapolis. For participants who were unable to travel, the research staff interviewed them in their home or at a local facility in their community. We conducted interviews with individual patients, individual caregivers or patient–caregiver dyads using a semi-structured interview guide to facilitate discussions about participants' experiences with TBI health services. The guide included several open-ended questions, including, '*What challenges have you faced in accessing care for TBI? What are the most important things for you in terms of services you receive for your TBI? What could be done better to facilitate better access to TBI services?*' It also included questions about specific barriers and facilitators to care identified in the literature, such as transportation and health insurance barriers. Interviews ranged 30–90 min based on whether it was a single participant (patient or caregiver) or patient–caregiver dyad interview.

2.2 | Data analysis

Due to limited knowledge in this area, we used an inductive approach in our data collection and analysis. A team of three analysts explored themes that emerged from the data consistent with constructivist grounded theory approach (Charmaz, 2006; Mills

et al., 2006). The team independently analysed a set of 15 transcripts (27% of all transcripts) to better understand the data and identify key themes. Identified themes were then compared and an initial coding structure was developed, which included specific codes to denote patients versus caregivers. We then conducted open coding and used an iterative process to refine and sort codes into categories (Auerbach and Silverstein, 2003; Guest et al., 2011; Saldaña, 2015). A finalised coding list was then applied to all transcripts using Atlas.ti. We reviewed and coded the data until we reached thematic saturation (i.e. new information or variations of themes in the data could not be identified; Guest et al., 2011). We also conducted additional analyses based on characteristics such as time since injury, insurance status (private vs. public) and residency status (urban vs. rural) to identify subgroup differences and contextual factors that may have influenced participants' experiences.

2.3 | Findings

Our sample included 62 participants (34 patients, 28 caregivers), including 21 patient–caregiver dyads. Age ranged from 20 to 89 (mean = 58) years. Of the 34 patients, 41% were ≤ 4 years post-injury, 35% were 5–10 years post-injury and 20% were ≥ 10 years post-injury. Forty-five percent (45%) of participants reported living in rural areas, and 65% of patients and 43% of caregivers had publicly funded health insurance (e.g. Medicaid). Demographic data are summarised in Table 1.

Patients' (PT) and caregivers' (CG) experiences with TBI care navigation are characterised by three major challenges: lack of support with care navigation, financial barriers and communication barriers. Here, we detail participants' experiences of these challenges, highlight barriers and facilitators to health services navigation and provide suggestions for improvement.

2.4 | Lack of navigation support

In their narratives about health services navigation for TBI, participants discussed how post-acute TBI care remains complex, often involving multiple providers and specialty care. It also requires effective healthcare communication and care coordination between providers and facilities. Participants shared their experiences navigating complex healthcare systems, reporting general frustration and feelings of loss due to limited support and guidance during this process. For example, they discussed how, as patients and caregivers, they relied on healthcare providers for information about TBI health services. However, many providers were not knowledgeable about services or did not provide any guidance on follow-up care for TBI.

> Frankly, they [social workers] are worthless. They're worthless. … The social worker gave me nothing at

TABLE 1 Participant demographics

	Patients (n)	Caregivers	Total
Gender			
Male	18	10	28
Female	16	18	34
Location			
Rural	15	13	28
Urban	19	15	34
Age (in years)			
18–29	5	0	5
30–49	7	4	11
50–64	14	12	26
>65	8	12	20
Time	Since Accident	As Caregiver	
0–4 years	13	15	28
5–10 years	12	9	21
>10 years	9	4	13
Type of Injury			
Automotive Accident	21		
Fall	6		
Other (Sports/Work)	7		
Marital status			
Divorced	8	3	11
Married	16	23	39
Never Married	9	0	9
Widowed	1	2	3
Education			
High School/GED	9	6	15
Some College/ Associate's	12	6	18
Bachelor's	8	10	18
Graduate Degree	5	6	11
Employment			
Unemployed	13	4	17
Employed	6	10	16
On Disability	10	1	11
Retired	5	13	18
Income			
>10 k	4	0	4
10 k–39,999	21	10	31
40 k–69,999	2	6	8
70 k–99,999	2	4	6
≥100 k	3	6	9
Did not answer	2	2	4
Insurance (at time of interview)			
Private/Other	12	14	26
Medicare/Medicaid	22	12	34
No Insurance	0	2	2

[local hospital]. Now, they were a little better here [rehabilitation hospital]. But still, it was so soon in the recovery. I mean, they got me to the next step, and then it was my job to find the next step. You stop at outpatient, and then there's nothing. I don't want to be so bleak, but this is the reality of brain injury. … There is no continuum of care after you leave the hospitals. Let's just be honest. There isn't. [CG8].

But I don't know where to go. I don't even know who to call. … I can never talk to [my doctor]. I can never even get a phone call back from her nurse, and the things that I have done are because we have done it. … It's been six months, and I still don't have a PCP (primary care provider). I still haven't found a neurologist. … A neurologist that will do my eyes. None of that. That's just stuff that we have found. [PT63 and CG52].

Participants also described how lack of access to and difficulties understanding TBI health information undermined health-seeking behaviours for TBI care and their participation in treatment decisions. A caregiver illustrates this as she discussed her struggles to identify appropriate care for her loved one.

I sat for four or five hours trying to read through the list of services that are available and trying to understand what applies. My goodness! It's overwhelming and not wanting to ever do anything that would be inappropriate. You know, we talked with the doctor. These are the needs that we have. She's already meeting with vocational rehab but that's not going anywhere (sigh). So what do we do in the meantime, you know? And is it appropriate to see out this service and this service? How do you navigate that? I don't have answers there. That's been hard. [CG16].

Indeed, many participants in the study struggled with navigating outpatient care post-TBI. They reported difficulties identifying and accessing services for TBI care due to lack of information and support as well as the complexity of TBI care management.

2.5 | Financial barriers

Financial barriers undermined participants' ability to navigate TBI health services. In fact, financial cost of TBI care dominated participants' narratives about healthcare navigation. About 44% of participants discussed experiencing financial barriers to TBI care navigation during their interview. Notably, 83% of patients ≥ 10 years post-TBI and 55% of patients 5–10 years post-TBI reported prolonged experiences with financial barriers associated with TBI care.

In their narratives, participants underscored the mismatch between their experience of TBI as a chronic health condition requiring ongoing treatment (e.g. long-term physical therapy) and limited availability of long-term insurance coverage for TBI-related symptoms or health conditions. They discussed how exorbitant costs associated with TBI quickly depleted their healthcare benefits and personal savings, leaving them with limited safety nets for healthcare needs. In the first excerpt below, a caregiver highlights the incongruency between patients' needs and available health resources, as well as lack of effective policies that support long-term care for TBI. She also called for a reconstructed view of TBI as a 'lifetime issue' and advocated additional funding to support ongoing therapy for TBI patients. In the second excerpt, a caregiver explained how lack of healthcare coverage undermined the patients' recovery and access to needed physical therapy.

> I think the most important thing is to realize [that for] anyone with a brain injury, it's a lifetime issue. You can't just fix it like a broken arm and move on. If our society could understand that funding for people is so important [so] that they continue therapy... I think our system is failing brain injury [patients] right now in that regard. [CG8] .

> Well, it [insurance] doesn't cover anything (laughter). ... It's hit hard because he [patient] was not able to get the care that he needed for the physical therapy, neuro side. Any neuro stuff, anything that has to do with brain injury, [state insurance] does not recognize at all. Nothing. [CG44].

Moreover, participants who were underinsured, uninsured or who relied on public healthcare insurance such as Medicaid and social security benefits reported even greater financial burden as they became more dependent on illusive and limited safety net measures for care. For example, participants with Medicaid shared that few providers accept public health insurance and that healthcare coverage was sporadic, further limiting access to adequate TBI care. Most participants (64%) had Medicaid at the time of the interview, and 94% of these participants reported ongoing financial barriers to care.

> Between looking for that and trying to work with Medicaid and Social Security and bankruptcy, yeah. It was hell. ... Okay, well maybe it was July of 2014 when it [insurance] ran out, because that's when we started working to get him into [facility]. [CG37 and PT26].

> We had to fight to get him to [long-term facility]. Because when he left here [rehabilitation hospital], he still wasn't quite on Medicaid. ... I think that he was on Medicaid, but they hadn't given him permission to go to [facility] yet. So we were waiting on that permission. He had to come home for a couple of weeks.

> ... Every lunch hour, I was calling. I was dealing with Medicaid. [CG48].

In additional to financial barriers, participants maintained that seeking and accessing TBI care were time consuming, complex, obscure and emotionally exhausting. The excerpts below exemplify the emotional labour many patients and caregivers underwent to ensure adequate services were received. They also illustrate the complex bureaucracy of health insurance coverage and associated challenges, such as interpreting convoluted information about insurance coverage and organising, comprehending, negotiating and paying healthcare bills.

> We had a representative from our insurance company. It cost us like $1,500 to have her help manage bills. ... We would get literally hundreds of itemized bills that were like 6,000 pages. ... We had a $392,000 bill. ... If I didn't have anybody to help me, there's no way that I would have been able to call people and have any idea what they were talking about. Complicated is an understatement. You never talk to the same person until we had that representative. ... I went bankrupt. [PT65].

> I could not get an answer from [insurance company] as to whether they would pay to transfer [patient] from hospital to rehabilitation center. I went on for two months. [They kept saying] "I'll call you back in two days. I have to check." They didn't call back. ... I called again, and I've finally tried to talk to supervisors and got nowhere. So we went down to their call center in town, and I just told them, "I don't have a gun. I'm not armed. But I'm not leaving until somebody answers my question." And that's what we did. ... I couldn't get an answer anywhere, and I have spent my entire life in the last four years on the phone. [CG30 and PT32].

Participants above emphasised the time demand for navigating TBI health services, which resonated with other study participants. Many participants experienced financial burden and financial barriers to health services navigation several years post-injury.

2.6 | Communication barriers

Communication barriers also permeated participants' narratives about TBI healthcare navigation. Many participants received limited information about TBI symptoms, treatment expectations and outcomes from healthcare providers. This lack of information undermines patients' health literacy about TBI and weakens their ability to navigate and access needed services. A patient who survived a major TBI described leaving the hospital with only a few sheets of paper about her condition and medications. She described feeling ill informed and eventually requested her medical records to learn more about her condition.

What we were given out when we left here [rehabilitation hospital] was a few sheets of paper. Less than ten pieces of paper. One had my medicines. One had what I had and what injuries. And then we asked for the medical record. No, I do not feel informed at all [about TBI]. [PT.63].

Participants also claimed that many healthcare providers lack knowledge of TBI and were unable to guide them through their survivorship journey. Consequently, several participants shared that they rely on the internet for information about TBI progression and long-term care options. However, only those with higher levels of education and social resources were able to conduct their own research; participants with lower health literacy had fewer places to turn for information. The excerpts below demonstrate the challenges that many patients and caregivers experience.

If the internet hadn't been invented yet, we'd be screwed. Honestly, that's been our main way of getting some information. … It's not from here [inpatient facility] or [outpatient facility] or anywhere else. … We have just had to do it on our own and try to find somebody that knows something about TBIs, which is a chore. [CG52 and PT63].

For so many years we were on survival, and I didn't have time to do research or be an advocate like some people do. … I have a learning disability and didn't learn to read until I was in third grade. … I don't seek out other reading that much. [CG18 and PT27].

While most participants voiced concerns over limited access to TBI care information, others identified information overload and providers' medical jargon as barriers to effective TBI health communication. They felt overwhelmed when providers shared a lot of information in moments of crisis, using medical terms that were difficult for lay individuals to understand. In contrast, others discussed leaving treatment decisions to caregivers without providing much education or support to facilitate shared decision-making.

When people have presented me with options and explained options, I've always felt like I can choose what's best for him [patient]. … It's just if someone says, "Okay, here he is. What do you wanna do?" Then I feel like I don't have a clue. I don't know what to do. [CG46].

2.7 | Suggested recommendations for navigating health services for TBI

To address barriers to accessing TBI healthcare and facilitate care coordination, participants suggested broadening patient navigation resources. They stated that a healthcare navigator could help patients and caregivers overcome barriers to care navigation. Specifically, a patient navigator may assist patients and caregivers with accessing and understanding TBI care information and serve as a liaison between patients, families, providers and clinical care teams.

A few participants noted that they had a case manager or social worker who served in a similar role and that having such a person elevated the quality of care their loved ones received during their inpatient hospital stay. However, this service was not systematically or readily available to everyone in inpatient care and was less accessible for outpatient care. To illustrate, in the first excerpt, a caregiver reiterated gaps in care navigation discussed above and suggested the need for a patient advocate to support families and facilitate care navigation. In the second excerpt, another caregiver shared her experience with a social worker who provided care navigation support and discussed its impact on her healthcare experiences.

There needs to be a patient advocate. I know that they have case managers. But there needs to be more so that each person has somebody that they can work with and not just one for like 50 people …because they don't have the time to deal with everything. A lot of families don't know how to go about getting what they need. [CG48].

When this [TBI] first happened. … It was so emotionally traumatic. One of the best things was when the person from [inpatient facility] came to the hospital. It felt like there was a handhold…. If there is some way to make that last longer for patients and their family, that would be really beneficial. … She came to the hospital and said, "Here is what's gonna happen now. And this is what's gonna happen next." She kind of laid out a little timeframe for us. … We knew what was coming. [CG57].

Regarding financial barriers, participants acknowledged that substantial resources and changes in health insurance policy and legislation are required to adequately address the financial burden that patients and families experience after TBI. However, they noted that more immediate and measured steps may be taken to assist patients and families in coping with the financial barriers to care. For example, healthcare navigators may assist with identifying existing financial and healthcare resources since many patients are unaware of available services and treatment recommendations. In addition, participants suggested that supporting volunteer and local organisations, such as community support groups, may help fill critical gaps in patients' informational, financial and social support needs. Several participants were support group members and shared how these groups helped fill some of the gaps created by lack of health and social services for TBI patients. A participant discussed in the quote below some long-term issues patients and families face but are often unprepared to manage. He suggested how support groups may be able to link patients and caregivers to resources to better navigate TBI health services.

Maybe offer a class once or twice a year on just how to set things in motion financially. Get an attorney to come and spend half a day with them walking them through the steps for what this new event really means. Are you going to have to take guardianship of your adult, 35-year-old daughter because she's not capable? Are you going to have to think about long-term financial planning for when you can no longer take care of your wheelchair-bound person because you are going to age out? Who is going to advocate when you're not there? [PT25].

While support groups may be beneficial to some, participants acknowledged their limited reach to marginalised, hard-to-reach patients who may benefit most from such resources. They also discussed barriers to support group participation, such as transportation and financial barriers.

3 | DISCUSSION

Our findings offer insights into the lived experiences of patients struggling with TBI care navigation. Drawing from participant narratives, our findings emphasise the need for care navigation support throughout the TBI care continuum. Systematic patient navigation may be a useful approach to overcoming barriers to care and improving care navigation for TBI patients and families, including navigation of transfer of care (e.g. from inpatient to rehabilitation services), community reintegration, coordinating care and engagement in health services post-TBI hospitalisation.

Patient navigation is an internationally utilised, culturally grounded, patient-centred care service delivery model that optimises patients' interface with the healthcare system (Simon et al., 2016; Valaitis et al., 2017). Patient navigation was first introduced in cancer care in the U.S., with the goal to reduce healthcare disparities for underserved patient populations (Freeman & Rodriguez, 2011; Vargas et al., 2008). It seeks to reduce barriers to care by promoting timely access to care and providing support to patients throughout the care continuum, from cancer diagnosis to survivorship (Plant et al., 2013; Robinson-White et al., 2010). Navigators could be licensed professionals (e.g. nurses and social workers) or lay health workers devoted to working with patients and families to help address their needs, including assisting with insurance, explaining treatment and care options, managing medical paperwork, facilitating communication with healthcare teams and providing support (Robinson-White et al., 2010). This care model has been widely successful in helping patients navigate complex health systems and has been shown to increase access to health screenings, improve adherence to treatment and facilitate productive health communication (Ali-Faisal et al., 2017; Freeman & Rodriguez, 2011; Rosario et al., 2017; Vargas et al., 2008).

While patient navigation has not been widely tested for patients with chronic disabilities, such as TBI, emerging studies are promising.

Rosario et al. (2017) showed that TBI patients who participated in a navigator intervention were offered tailored support that aided in community integration, reduced re-hospitalisation rates and falls and improved functional outcomes. Case management and resource facilitators, which assist TBI patients and survivors with vocational rehabilitation, should also be consistently and widely available to help families navigate TBI care and community resources. A recent study reported that care fragmentation for TBI patients was pervasive and that most patients and caregivers often do not have a cohesive plan that supports transition of care from intensive, acute services to community reintegration. The study recommended a link person to help oversee patient journeys and improve care integration (Abrahamson et al., 2017). Case management has been shown to improve patient survivorship, including increased functioning and decreased social isolation (Arnold & Elder, 2013; Ashley et al., 1994; Trexler et al., 2010 and may play an important role in care coordination and navigation for families in need, especially those who are marginalised. However, access to case management is not widely available.

Our results suggest a disconnect between TBI's long-term health impacts and associated financial costs, and the financial barriers to successful TBI care navigation. It is important to emphasise that financial barriers to healthcare are not unique to TBI patients. Although the costs of acute care and rehabilitation programs for TBI are substantial and well-documented (Humphreys et al., 2013; Stroupe et al., 2013; Taylor et al., 2017), TBI's economic impact on patients and their families (especially long-term financial burden) is less understood (Malec et al., 2017). Participants' narratives of financial barriers to care navigation provide qualitative evidence of significant financial burden and resulting stress on families and contribute to a better understanding of the economic impacts of chronic conditions like TBI.

Our findings underscored the added financial burden for disadvantaged individuals (lacking social, financial and educational resources) who rely on public health insurance. These individuals are at greater risk of experiencing healthcare disparities. These disparities may be amplified in rural areas with limited TBI care options and resources. Indeed, a recent study indicated that many rural residents with TBI lacked knowledge of services and struggled to find qualified TBI care providers (Solovieva & Walls, 2014). Similarly, community healthcare providers often lack TBI expertise, which impacts access to quality healthcare for patients (Matarazzo et al., 2016). Our findings provide additional evidence to support specialised TBI training for healthcare providers to meet the needs of TBI survivors.

This study also highlights communication barriers faced by patients navigating TBI care. Unavailability of comprehensive and reliable TBI patient education and TBI treatment across the care continuum combined with ineffective patient–provider communication undermine patients' engagement in health services. As our findings show, participants often relied on internet research to educate themselves about TBI and expressed frustration with lack of information about their injury and comorbid conditions. To our

knowledge, there has not been any study on patient–provider communication specific to TBI. A recent study on TBI-related beliefs among U.S. military veterans with TBI reported that participants had limited understanding of TBI nomenclature, recovery expectations, trajectories and impact of co-occurring mental health diagnoses (King et al., 2018). Our study identified opportunities for improved patient education and future research studies to examine patient–provider communication in TBI care, especially those that will help participation in shared treatment decision-making.

This study has several limitations. It included a purposive sample and may not be generalisable to all patients and caregivers throughout Indiana or beyond. It only included English speakers and many of our participants were engaged in care that included community support groups. The experiences of individuals not receiving any type of support or services (perhaps due to barriers to care) and non-English speakers remain unknown. Moreover, a few participants reported that they had mild cognitive or communication impairment following their injury, which may have influenced their experiences. However, we drew from their caregiver's account to corroborate evidence. We also treated patient–caregiver dyads as a single unit and did not analyse differences between patients' and caregivers' experiences. Future studies are encouraged to include a more diverse sample of patients and caregivers and to examine the experiences of individuals with TBI who are marginalised in healthcare.

This study incorporated multiple perspectives from patients with TBI and their caregivers that deepened our understanding of the navigation challenges for TBI care in complex healthcare systems. Our findings point to an urgent need to provide short- and long-term navigation support for TBI care and to improve disease education and patient–provider communication for patients and their caregivers.

CONFLICT OF INTEREST STATEMENT

The authors report no conflict of interest.

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ORCID

Johanne Eliacin https://orcid.org/0000-0001-8027-2935

REFERENCES

Abrahamson, V., Jensen, J., Springett, K., & Sakel, M. (2017). Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: A qualitative study. *Disability and Rehabilitation*, *39*, 1683–1694. https://doi.org/10.1080/09638288.2016.1211755

Ali-Faisal, S. F., Colella, T. J. F., Medina-Jaudes, N., & Scott, L. B. (2017). The effectiveness of patient navigation to improve healthcare utilization outcomes: A meta-analysis of randomized controlled trials. *Patient Education and Counseling*, *100*, 436–448. https://doi.org/10.1016/j.pec.2016.10.014

Andelic, N., Sigurdardottir, S., Arango-Lasprilla, J. C., & Godbolt, A. K. (2016). Long-term functional and psychosocial consequences and health care provision after traumatic brain injury. *Behavioural Neurology*, *2016*, 1–3. https://doi.org/10.1155/2016/2678081

Arnold, S., & Elder, M. (2013). Case management: The allocation of hours and influencing factors in the management of survivors of traumatic brain injury. *Care Management Journal*, *14*, 2–10. https://doi.org/10.1891/1521-0987.14.1.2

Ashley, M. J., Persel, C. S., Lehr, R. P. J., Feldman, B., & Krych, D. K. (1994). Post-acute rehabilitation outcome: Relationship to case-management techniques and strategy. *Journal of Insurance Medicine (New York, NY)*, *26*, 348–354.

Auerbach, C. F., & Silverstein, L. B. (2003). *Qualitative data: An introduction to coding and analysis*. NYU Press.

Bernard, H. R. (2011). *Research methods in anthropology: Qualitative and quantitative approaches*. AltaMira.

Brain Injury Fact Sheet: CICOA. (2020). Retrieved October 07, 2020, from https://cicoa.org/resource-center/faqs/brain-injury-fact-sheet/

Brodaty, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry*, *20*, 537–546. https://doi.org/10.1002/gps.1322

Centers for Disease Control and Prevention. (2019). Surveillance Report of Traumatic Brain Injury-related Emergency Department Visits, Hospitalizations, and Deaths—United States, 2014. Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. Retrieved from: https://www.cdc.gov/traumaticbraininjury/pdf/TBISurveillance-Report-FINAL_508.pdf

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative research*. Sage.

Corrigan, J. D., & Bogner, J. (2007). Initial reliability and validity of the Ohio State University TBI Identification Method. *The Journal of Head Trauma Rehabilitation*, *22*, 318–329. https://doi.org/10.1097/01.HTR.0000300227.67748.77

Decker, G. (2007). Navigators: The champions of finding solutions to healthcare barriers. *ONS Connect*, *22*, 29.

deGuise, E., LeBlanc, J., Feyz, M., Meyer, K., Duplantie, J., Thomas, H., Abouassaly, M., Champoux, M.-C., Couturier, C., Lin, H., Lu, L., Robinson, C., & Roger, E. (2008). Long-term outcome after severe traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *23*(5), 294–303. https://doi.org/10.1097/01.HTR.0000336842.53338.f4

Dismuke, C. E., Walker, R. J., & Egede, L. E. (2015). Utilization and cost of health services in individuals with traumatic brain injury. *Global Journal of Health Science*, *7*, 156–169. https://doi.org/10.5539/gjhs.v7n6p156

Driscoll, M. A., Knobf, M. T., Higgins, D. M., Heapy, A., Lee, A., & Haskell, S. (2018). Patient experiences navigating chronic pain management in an integrated health care system: A qualitative investigation of women and men. *Pain Medicine*, *19*, S19–S29. https://doi.org/10.1093/pm/pny139

Eliacin, J., Fortney, S., Rattray, N. A., & Kean, J. (2018). Access to health services for moderate to severe TBI in Indiana: Patient and caregiver perspectives. *Brain Injury*, *32*, 1510–1517. https://doi.org/10.1080/02699052.2018.1499964

Fouad, M. N., Acemgil, A., Bae, S., Forero, A., Lisovicz, N., Martin, M. Y., Oates, G. R., Partridge, E. E., & Vickers, S. M. (2016). Patient

navigation as a model to increase participation of african americans in cancer clinical trials. *Journal of Oncology Practice*, *12*, 556–563. https://doi.org/10.1200/JOP.2015.008946

Freeman, H. P., & Rodriguez, R. L. (2011). History and principles of patient navigation. *Cancer*, *117*(15 Suppl), 3539–3542. https://doi.org/10.1002/cncr.26262

Gimpel, N., Marcee, A., Kennedy, K., Walton, J., Lee, S., & DeHaven, M. J. (2010). Patient perceptions of a community-based care coordination system. *Health Promotion Practice*, *11*, 173–181. https://doi.org/10.1177/1524839908320360

Griesbach, G. S., Kreber, L. A., Harrington, D., & Ashley, M. J. (2015). Post-acute traumatic brain injury rehabilitation: Effects on outcome measures and life care costs. *Journal of Neurotrauma*, *32*, 704–711. https://doi.org/10.1089/neu.2014.3754

Guest, G., MacQueen, K. M., & Namey, E. E. (2011). *Applied thematic analysis*. Los Angeles, London, New Delhi: Sage.

Hossain, W. A., Ehtesham, M. W., Salzman, G. A., Jenson, R., & Calkins, C. F. (2013). Healthcare access and disparities in chronic medical conditions in urban populations. *Southern Medical Journal*, *106*, 246–254. https://doi.org/10.1097/SMJ.0b013e31828aef37

Humphreys, I., Wood, R. L., Phillips, C. J., & Macey, S. (2013). The costs of traumatic brain injury: A literature review. *ClinicoEconomics and Outcomes Research: CEOR*, *5*, 281. https://doi.org/10.2147/ceor.s44625

Indiana State Department of Health. Traumatic brain injury. Retrieved from https://www.in.gov/isdh/files/TBI.pdf

Kadushin, C. (1968). Power, influence and social circles: A new methodology for studying opinion makers. *American Sociological Review*, *33*, 685. https://doi.org/10.2307/2092880

King, P. R., Beehler, G. P., Vest, B. M., Donnelly, K., & Wray, L. O. (2018). Qualitative exploration of traumatic brain injury-related beliefs among US military veterans. *Rehabilitation Psychology*, *63*, 121. https://doi.org/10.1037/rep0000165

Koch, G., Wakefield, B. J., & Wakefield, D. S. (2015). Barriers and facilitators to managing multiple chronic conditions: A systematic literature review. *Western Journal of Nursing Research*, *37*, 498–516. https://doi.org/10.1177/0193945914549058

Leith, K. H., Phillips, L., & Sample, P. L. (2004). Exploring the service needs and experiences of persons with TBI and their families: The South Carolina experience. *Brain Injury*, *18*, 1191–1208. https://doi.org/10.1080/02699050410001719943

Lloyd, B. T., & Stirling, C. (2011). Ambiguous gain: Uncertain benefits of service use for dementia carers. *Sociology of Health & Illness*, *33*, 899–913. https://doi.org/10.1111/j.1467-9566.2010.01332.x

Malec, J. F., Van Houtven, C. H., Tanielian, T., Atizado, A., & Dorn, M. C. (2017). Impact of TBI on caregivers of veterans with TBI: Burden and interventions. *Brain Injury*, *31*, 1235–1245. https://doi.org/10.1080/02699052.2016.1274778

Masel, B. E., & DeWitt, D. S. (2010). Traumatic brain injury: A disease process, not an event. *Journal of Neurotrauma*, *27*, 1529–1540. https://doi.org/10.1089/neu.2010.1358

Matarazzo, B. B., Signoracci, G. M., Brenner, L. A., & Olson-Madden, J. H. (2016). Barriers and facilitators in providing community mental health care to returning veterans with a history of traumatic brain injury and co-occurring mental health symptoms. *Community Mental Health Journal*, *52*, 158–164. https://doi.org/10.1007/s10597-015-9926-9

Mills, J., Bonner, A., & Francis, K. (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*, *12*, 8–13. https://doi.org/10.1111/j.1440-172X.2006.00543.x

Muhr, T. (2012). *AtlasTI: Scientific Software Development GmbH*. Retrieved from: atlasti.com/about-atlas-ti

Oyesanya, T. O., Arulselvam, K., Thompson, N., Norelli, J., & Seel, R. T. Health, wellness, and safety concerns of persons with moderate-to-severe traumatic brain injury and their family caregivers: A qualitative content analysis. *Disability and Rehabilitation*, *2*, 1–11. https://doi.org/10.1080/09638288.2019.1638456

Palys, T. (2008). *Basic research. The Sage encyclopedia of qualitative research methods*. Sage.

Peel, E., & Harding, R. (2014). 'It's a huge maze, the system, it's a terrible maze': Dementia carers' constructions of navigating health and social care services. *Dementia*, *13*, 642–661. https://doi.org/10.1177/1471301213480514

Plant, N., Mallitt, K.-A., Kelly, P. J., Usherwood, T., Gillespie, J., Boyages, S., Jan, S., McNab, J., Essue, B. M., Gradidge, K., Maranan, N., Ralphs, D., Aspin, C., & Leeder, S. (2013). Implementation and effectiveness of 'care navigation', coordinated management for people with complex chronic illness: Rationale and methods of a randomised controlled trial. *BMC Health Services Research*, *13*, 164. https://doi.org/10.1186/1472-6963-13-164

Protheroe, J., Nutbeam, D., & Rowlands, G. (2009). Health literacy: A necessity for increasing participation in health care. *British Journal of General Practice: The Journal of the Royal College of General Practitioners*, *59*, 721–723. https://doi.org/10.3399/bjgp09X472584

Pugh, M. J., Finley, E. P., Wang, C.-P., Copeland, L. A., Jaramillo, C. A., Swan, A. A., Elnitsky, C. A., Leykum, L. K., Mortensen, E. M., Eapen, B. A., Noel, P. H., & Pugh, J. A. (2016). A retrospective cohort study of comorbidity trajectories associated with traumatic brain injury in veterans of the Iraq and Afghanistan wars. *Brain Injury*, *30*, 1481–1490. https://doi.org/10.1080/02699052.2016.1219055

Pundlik, J., Perna, R., & Arenivas, A. (2020). Mild TBI in interdisciplinary neurorehabilitation: Treatment challenges and insights. *NeuroRehabilitation*, *46*(2), 227–241. https://doi.org/10.3233/NRE-192971. PMID: 32083602

Reis, C., Wang, Y., Akyol, O., Ho, W., Ii, R., Stier, G., Martin, R., & Zhang, J. (2015). What's new in traumatic brain injury: update on tracking, monitoring and treatment. *International Journal of Molecular Sciences*, *16*, 11903–11965. https://doi.org/10.3390/ijms160611903

Robinson-White, S., Conroy, B., Slavish, K. H., & Rosenzweig, M. (2010). Patient navigation in breast cancer: A systematic review. *Cancer Nursing*, *33*, 127–140. https://doi.org/10.1097/NCC.0b013e3181c40401

Rockhill, C. M., Jaffe, K., Zhou, C., Fan, M. Y., Katon, W., & Fann, J. R. (2012). Health care costs associated with traumatic brain injury and psychiatric illness in adults. *Journal of Neurotrauma*, *29*, 1038–1046. https://doi.org/10.1089/neu.2010.1562

Rosario, E. R., Espinoza, L., Kaplan, S., Khonsari, S., Thurndyke, E., Bustos, M., Vickers, K., Navarro, B., & Scudder, B. (2017). Patient navigation for traumatic brain injury promotes community re-integration and reduces re-hospitalizations. *Brain Injury*, *31*, 1340–1347. https://doi.org/10.1080/02699052.2017.1325937

Rotondi, A. J., Sinkule, J., Balzer, K., Harris, J., & Moldovan, R. (2007). A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *The Journal of Head Trauma Rehabilitation*, *22*, 14–25. https://doi.org/10.1097/00001199-200701000-00002

Ryvicker, M. (2018). A conceptual framework for examining healthcare access and navigation: A behavioral-ecological perspective. *Social Theory & Health*, *16*, 224–240. https://doi.org/10.1057/s41285-017-0053-2

Saldaña, J. (2015). *The coding manual for qualitative researchers*. Los Angeles, London, New Delhi, Singapore, Washington, D.C.: Sage.

Sample, P. L., & Langlois, J. A. (2005). Linking people with traumatic brain injury to services: Successes and challenges in Colorado. *The Journal of Head Trauma Rehabilitation*, *20*, 270–278. https://doi.org/10.1097/00001199-200505000-00009

Schulz-Heik, R. J., Poole, J. H., Dahdah, M. N., Sullivan, C., Adamson, M. M., Date, E. S., Salerno, R., Schwab, K., & Harris, O. (2017). Service needs and barriers to care five or more years after moderate to

severe TBI among veterans. *Brain Injury*, 31, 1287–1293. https://doi.org/10.1080/02699052.2017.1307449

Shaw, A., Ibrahim, S., Reid, F., Ussher, M., & Rowlands, G. (2009). Patients' perspectives of the doctor-patient relationship and information giving across a range of literacy levels. *Patient Education and Counseling*, 75, 114–120. https://doi.org/10.1016/j.pec.2008.09.026

Shockney, L. D. (2010). Evolution of patient navigation. *Clinical Journal of Oncology Nursing*, 14, 405–407. https://doi.org/10.1188/10.CJON.405-407

Simon, M. A., Samaras, A. T., Nonzee, N. J., Hajjar, N., Frankovich, C., Bularzik, C., Murphy, K., Endress, R., Tom, L. S., & Dong, X. (2016). Patient navigators: Agents of creating community-nested patient-centered medical homes for cancer care. *Clinical Medicine Insights: Women's Health*, 25(9), 27–33. https://doi.org/10.4137/CMWH.S39136

Smith, J. E., & Smith, D. L. (2000). No map, no guide: Family caregivers' perspectives on their journeys through the system. *Care Management Journals*, 2, 27–33.

Solovieva, T. I., & Walls, R. T. (2014). Barriers to traumatic brain injury services and supports in rural setting. *Journal of Rehabilitation*, 80, 10–18.

Stocchetti, N., & Zanier, E. R. (2016). Chronic impact of traumatic brain injury on outcome and quality of life: A narrative review. *Critical Care*, 20, 148. https://doi.org/10.1186/s13054-016-1318-1

Stroupe, K. T., Smith, B. M., Hogan, T. P., St. Andre, J. R., Pape, T., Steiner, M. L., Proescher, E., Huo, Z., & Evans, C. T. (2013). Healthcare utilization and costs of Veterans screened and assessed for traumatic brain injury. *Journal of Rehabilitation Research & Development*, 50, 1047–1068. https://doi.org/10.1682/jrrd.2012.06.0107

Taylor, B. C., Hagel Campbell, E., Nugent, S., Bidelspach, D. E., Kehle-Forbes, S. M., Scholten, J., Stroupe, K. T., & Sayer, N. A. (2017). Three year trends in veterans health administration utilization and costs after traumatic brain injury screening among veterans with mild traumatic brain injury. *Journal of Neurotrauma*, 34, 2567–2574. https://doi.org/10.1089/neu.2016.4910

Trexler, L. E., Trexler, L. C., Malec, J. F., Klyce, D., & Parrott, D. (2010). Prospective randomized controlled trial of resource facilitation on community participation and vocational outcome following brain injury. *The Journal of Head Trauma Rehabilitation*, 25, 440–446. https://doi.org/10.1097/HTR.0b013e3181d41139

Valaitis, R. K., Carter, N., Lam, A., Nicholl, J., Feather, J., & Cleghorn, L. (2017). Implementation and maintenance of patient navigation programs linking primary care with community-based health and social services: A scoping literature review. *BMC Health Services Research*, 17(1), 116. https://doi.org/10.1186/s12913-017-2046-1

Vargas, R. B., Ryan, G. W., Jackson, C. A., Rodriguez, R., & Freeman, H. P. (2008). Characteristics of the original patient navigation programs to reduce disparities in the diagnosis and treatment of breast cancer. *Cancer*, 113(2), 426–433. https://doi.org/10.1002/cncr.23547