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Living with traumatic brain injury in a rural setting: Supports and barriers across the continuum of care

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Abstract

Purpose—Traumatic brain injury (TBI) is prevalent in Kentucky and comes with a high cost in care and quality of life for individuals and caregivers affected. Many people living with the condition of TBI have unmet needs. Research among people living with TBI in rural areas is limited. The purposes of this study were to 1) increase understanding of the lived experience of people with TBI and caregivers in rural regions of Kentucky across the continuum of their care and 2) provide their perspectives on barriers and facilitators of optimal function and well-being.

Methods—A qualitative descriptive interview study was conducted by a multidisciplinary team. Content analysis was completed with data-derived coding and iterative modifications to analysis, coalescing codes into categories and themes.

Results—Thirteen people with TBI and six caregivers participated in the interview. Categories that emerged in analysis included the experiences under each locus of care; themes included relationships, functional competence, and participation in meaningful activity.

Conclusion—Relationships represented both barriers and facilitators of well-being. Major unmet needs persisted in terms of medical problems, support for caregivers, community linkages, and participation in meaningful activities. Recommendations are made regarding avenues for addressing unmet needs.

Keywords

rehabilitation; neurological injury; rural health care; caregiving

Background

Masel and DeWitt [32] emphasized that people with TBI have a chronic condition as defined by the World Health Organization [52]. The event of TBI causes or hastens the progression of secondary long term pathologies such as neurodegenerative disorders, neuroendocrine disorders, neuromuscular disorders, seizures, sleep dysfunction, psychiatric pathology, incontinence, sexual dysfunction, and metabolic dysregulation [32]. An analysis of re-hospitalization of people with TBI found a 20% rate in years one and five after the TBI for reasons such as general medical problems, seizures, psychiatric problems, fractures, and surgeries or procedures addressing problems sustained in the accident causing the TBI [31]. A recent study indicated older age, mechanism of injury being a fall, greater injury severity, rural residence, greater comorbidity and psychiatric comorbidity to all be significant predictors of re-hospitalization 3 years post-injury [43]. A leading task force from the Galveston Brain Injury Conference emphasized that people with TBI need support over their lifetime [29].

Corrigan [10] summarized eleven statewide assessments of people with TBI indicating that the majority had unmet needs in the areas of memory, income, job skills/employment, education, and stress management. Only 16% worked full time and 17% worked part time. Unmet needs identified in other research included social networking, transportation, balance and coordination difficulties and family stressors [18,21,26,27,33,36,47,53]. In Kentucky the findings were similar [50]. Levack and colleagues [27] completed a meta-analysis of qualitative studies examining the lived experiences of people with TBI and found several primary themes including: disconnects from one's previous self, social disconnect, emotional sequelae, the challenges of accessing internal and external resources, and challenges reconstructing their identity and place in the world.

Moreover, a Cochrane review of research examining effectiveness of intervention programs for people with TBI found little significant outcomes in quality of life, community reintegration or change in caregiver burden in response to interventions that were studied [48]. Research related to caregiver experiences is very limited, although Lefebvre, Cloutier, and Josee [25] found that the challenges experienced by caregivers were, not surprisingly, associated with the unmet needs of the individual with TBI. Caregiver demands are unique for each family [35] and assistance needed may include monitoring medications, managing challenging behaviors, adjusting to sexuality expression, responding to drug and alcohol abuse, and learning how to advocate for vital services [12]. Having someone with a moderate to severe TBI can impact every member of the family such as parents dealing with extended parenthood, spouses dealing with adjustments to partner roles, and siblings feeling neglected [12]. Caregiver stress has multifactorial negative outcomes. The caregiver is at risk for diminished health and quality of life, but the persons being cared for also have poorer physical and psychosocial outcomes when the caregiver experiences high levels of burden and depression [37]. Overlooked in published reports is the evolution of needs over time as care settings, functioning, and personal roles change. This change over time may account for the variety of findings in studies of TBI caregiver needs [37].

The Centers for Disease Control (CDC) indicated that people from rural areas were at increased risk for TBI [6]. Moreover, they were at increased risk of developing secondary medical conditions due to lack of availability and accessibility of medical and other resources, and rural residence is a predictor of re-hospitalization in the TBI population [43]. Two studies found that rural populations with TBI tended to be more functionally dependent, have lower health statuses at follow up, and have fewer resources for support [17,40]. One study demonstrated limited rehabilitation resources in rural areas of the United States, posing a significant barrier to outcomes [22]. Systemic barriers to rehabilitation and functional gains for those with TBI in rural areas included a lack of a coordinated approach among health care and community service providers, difficulties in locating appropriate services, challenges in identifying professionals with TBI expertise, and inability to find employment[22,41,46]. Bellon and colleagues [4] completed a study of people with acquired brain injury and caregivers, and found the top three themes related to family support needs were: 1) counselling and financial support, 2) family support groups, and 3) coordinated, accessible, and tailored services. Coordinated, accessible, and tailored services was identified more frequently by those living in rural and remote areas [4].

The scope and magnitude of the problem of chronic medical conditions among rural Kentuckians, especially those in Appalachian Kentucky, are well documented [11,20,39,44]. In 2014, 54 of Kentucky's 120 counties were classified as rural, and 42% of the Kentucky population had rural residency. All but nine of the 54 rural counties were economically distressed based on analysis of median income and poverty rate, and socioeconomic indicators (e.g. education, health, health care access, employment, income) were all lower in rural areas as compared to urban [9]. Traumatic brain injury (TBI) in Kentucky is prevalent and comes with a high cost of health care. The Kentucky Data Surveillance Network [3] determined that approximately 37,000 people sustained TBIs in Kentucky in 2013, with the primary mechanism of injury being motor vehicle accidents or falls. Of those, 33,593 were treated and released from an emergency department (ED), with ED charges estimated at \$140,346,239. An estimated 3,458 were hospitalized at a cost of \$205,496,481 for acute care direct costs or post-acute care charges for rehabilitation. Indirect costs related to chronic conditions and quality of life are difficult to quantify.

The Kentucky Appalachian Rural Rehabilitation Network (KARRN) initiated a series of studies to characterize the lives of people living with neurological impairments in rural Kentucky as a first step to improving services, support systems and quality of life among these populations. Two KARRN studies have been completed which examined the needs of people with spinal cord injury (SCI) [23] and stroke [11]. People with TBI are varied from those with SCI and stroke in impairments sustained, outcomes, and available financial and health care resources. This third study was designed to explore the experiences of people with TBI in rural areas.

Research among people living with TBI in rural areas is limited, and there is no published research on the recovery process and continuum of care following a TBI in rural Kentucky. The purposes of this study were to 1) increase understanding of the lived experience of people with TBI and caregivers in rural Kentucky across the continuum of their care and 2) to provide their perspectives on barriers and facilitators of optimal functioning and well-

being. This project focused exclusively on traumatic brain injury. Previously this research team conducted a similar study with people living with stroke [11] and we plan to examine the similarities and differences of these populations. This information will be used in the continued development of supports and linkages for people with TBI who live in rural areas.

Methods

A qualitative descriptive interview study [42] was conducted using a team approach [7]. A multidisciplinary research team consisting of a physical therapist, an occupational therapist, and a health communications specialist provided diverse professional perspectives in the interview and analysis process. This was deemed optimal because of the varied impairments people with TBI experience [15]. The institutional review boards for the University and for the health facilities whose databases were used in recruitment, approved the study.

The inclusion criteria for the individuals in this study were as follows: 1) People with traumatic brain injury sustained at least 6 months ago in order to find participants who had transitioned through the continuum of care, and/or a caregiver for the individual who sustained the TBI 2) Residence in Kentucky 3) Twenty-one years of age or older in order not to qualify as a minor per the Internal Review Board standards at the time and 4) Ability to participate in one interview (individual and/or caregiver) that lasts up to 60–90 minutes. Rural residency was examined using the USDA Rural-Urban Continuum Codes [49]. Approximately 125 recruitment flyers were mailed to former patients of two rehabilitation hospitals, identified from patient databases, who fit the inclusion criteria. Each respondent received a phone call to further identify inclusion criteria and informed consent was obtained from each participant.

Semi-structured, open-ended interviews [13] were conducted following development of the interview guide by the team through a series of team meetings (appendix A). Three researchers served as interviewers. Interview locations were determined by participants and included participants' homes, regional hospital meeting centers, and residential nursing facilities. Interviews with participant dyads (person with TBI and caregiver) or with participants separately were determined by participant preference. Demographic data including age, race, sex, ethnicity, education level, county of residence, occupation, employment status, marital status, annual income, current medications, number of TBIs and number of years post-TBI were also collected. The interviews typically lasted 90 minutes. To improve descriptive validity during the interview participants were asked to recount their experience in several ways. To increase interpretive validity, iterative questions were used to further clarify participants' responses. Field notes and reflective memos were recorded by the interviewer immediately post-interview. The interviews were audio recorded, transcribed verbatim, and checked for accuracy. All transcriptions were de-identified using participant self-selected pseudonyms.

Qualitative content analysis, the preferred approach to analysis for a qualitative descriptive study was completed with data-derived coding, and iterative modifications to analysis as new data were collected [42]. This project used a qualitative team approach. The goal for analysis was to achieve inter-coder agreement. Unlike inter-coder reliability that requires

that two or more equally capable coders operating in isolation from each other select the same code for the same unit of text, inter-coder agreement requires that two or more coders are able to reconcile through discussion whatever coding discrepancies they may have for the same unit of text [5]. This technique works well with qualitative team work, particularly if the team members come from different disciplines. For this project, the team analyzed the first three transcripts together to develop an agreed upon coding schema. At that point individual team members analyzed individual transcripts. After all the interviews were analyzed individually, a group discussion was conducted to again ensure team agreement on analysis and findings. This allowed for a final development of a categorization scheme through iterative analysis and rechecks by the entire research team. After agreement was reached on coding and categorization, individual researchers re-analyzed 2–3 interviews using the final categorization scheme. A team discussion of the final analysis and theme development took place. Each interviewer also triangulated the findings with their field notes and reflective memos that were developed with each interview. Finally member checks were conducted with three participants as analysis took place. The member checks confirmed our initial analysis.

Results

Thirteen individuals (10 male, 3 female) with TBI, and 6 caregivers (2 male, 4 female) were included in this study. Eleven of the individuals with TBI were able to verbally participate in the interview process. The remaining two individuals, although present during the interviews, were unable to communicate in the interview process with their caregivers due to physical limitations secondary to their injury. Ten different counties were represented in this study as seen in figure 1. A summary of the demographic information for all participants (caregivers and those with TBI) can be found in table 1 with specific demographic data by code name in table 2.

A descriptive summary of the participants' narratives across the continuum of care is presented categorically within the following structure: 1) TBI onset and emergency care 2) Acute care 3) Inpatient rehabilitation 4) Transitioning home and reintegration into the rural community.

TBI onset and emergency care

The TBI was caused by a motor vehicle accident for eleven of thirteen participants with one being the result of a self-inflicted gunshot wound, and one being due to complications from surgical removal of a brain tumor. The individuals with TBI were transported to the nearest hospital emergency department (ED) either by ambulance or helicopter. The majority of participants reported that the amount of time it took for the police, ambulance, and/or helicopter to arrive at the scene of the accident or event was very positive.

Individuals with TBI were unconscious during this time period and all were in a coma for varying amounts of time. Barriers noted with emergency care in the rural communities included the lack of neurologists on call, an inadequate knowledge base among practitioners, and participants' distrust in the local healthcare systems. One person with TBI, Murphy, reported that he was told by his father that his arm began to swell due to inappropriate

placement of the intravenous medication by staff at the local ED, and that his tracheal insertion site was damaged by poor tracheal placement. He described how his father wished they had immediately taken him to a university hospital in a nearby city instead of the rural local hospital.

... [my father] felt like he was not being supported by health care providers and they did not explain things to them.....That's one of the small town rural things... They don't trust what's in their community, number one because it is a small town so you hear about everything that goes on, but maybe it is that they're not as good either; who knows.

Murphy

There was often inconsistent and confusing communication about whether or not the person who had sustained the TBI would survive the trip from the local hospital ED to the next level of care. The caregivers all shared a significant amount of anxiety, fear, and feelings of helplessness during the ED experience.

(After arriving at the hospital), they just told us that it was very bad.they are not a level 1 hospital so we knew there was no (ability to monitor) ICP (intracranial pressure)and no neurologist. They were just letting us say goodbye to her; they did not think she would live. In fact, I turned around like this to say goodbye to my....cousin and she was with the head nurse and I saw the head nurse who was not looking at me say, she'll never make it to [a distant teaching hospital].

Cathy, Amanda's Mother

It was a pretty dark forecast for his life....I don't know if I initiated it or if they did but we (were)... thinking about his organ donation and so I was prepared to move ahead with that...it was such a shocking and stunning thing that you just...walk into something....before you realize what kind of decisions you're making.

Jaci, Brandon's mother

Acute care

All participants in local rural hospitals or EDs were transferred to larger hospitals in urban areas. Participants' descriptions of the acute care experience included both positive and negative interactions with health care providers. Some participants (caregivers) described that they felt they were given adequate information and understood what the doctors communicated to them.

(They)...gave us hope and...the feeling that it was going to be a hard road ahead... but possibly a decent outcome.

Cathy, Amanda's Mother

I remained impressed with how much attention they gave from 2–3 nurses all the time in the ICU.

Jaci, Brandon's Mother

One mother, whose son suffered a stroke during surgery for complications of his TBI, described how she felt the urban hospital displayed a lack of sensitivity and emotional support.

Some of them was pretty good; some of them, they was pretty bad... he was on life support and...they kept aggravating me and wanted me to pull the life support on him...and I told them no and they kept on.... I told her (the doctor) no, which I was glad she got off his case because then they done his surgery.... It...numbed me but then I had so much faith, I told them he wasn't going to die.....

Ella, Clay's mother

An additional challenge during the acute care phase was not having a place for family members to stay, since the hospital was far from their rural homes. Caregivers adapted in various ways, such as sleeping in stairwells or in uncomfortable chairs in waiting rooms. Caregivers had to adjust to living with only the essentials, and many had to miss work in order to be by their loved one's side. Murphy described the importance of family support:

My parents stayed with me... That's been a huge blessing....the entire time I was in the hospital, my parents were only not with me for one day.

Murphy

Inpatient rehabilitation

During the sub-acute phase, the majority of the people with TBI went to an inpatient rehabilitation facility (IRF) in an urban area. Often participants were unable to feed themselves, walk, shower, and use the restroom independently upon admission to the rehabilitation setting. This was frustrating, difficult, and scary.

I'd been out of it for a month; I didn't know anything for a month and then when I started coming to myself at (the urban IRF), I thought, what on earth has Roger put me in this crazy house for.

Sybil

When Dawson was asked about his challenges in the rehabilitation setting, he responded:

Well I tell you, when you're, when you're at a place like that and you ain't used to them,you know they're helping you...but still you're pretty scared..... and then I was in a lot of pain.... When you're used to being able to do everything and then you get to where you can't...that makes it pretty tough...you lose all your pride.... Wanting to get back to my family is more or less what kept me going. You're always worried about them when you ain't there to take care of them. Even if you ain't able, you think you are.

Dawson

Many participants described the acute IRF environments as places where expert support resulted in tangible positive change. Most of the participants with TBI reported that they started to regain their memory in these settings, and they began to realize how serious their functional limitations were. Small achievements with daily activities resulted in feelings of accomplishment. Many participants, who first were dependent upon the people around them,

were eventually able to return home with the ability to perform activities of daily living independently such as eating, showering, and dressing. Many shared experiences in which they were impressed and moved by the support and passion of the rehabilitation team.

I'll never forget her... I'd get so mad and she (the physical therapist) was doing the best for me.

Jesse

...anything compared to (the regional IRF in urban area)...will show to be inferior.

Murphy

Nathan spoke about how one of the speech therapists was able to help him not only with speech, but also with his memory and orientation, which helped when he had hallucinations.

...the floors would breathe, the walls would breathe, I would step out of the way for people who weren't there.

Nathan

Most felt that their loved ones/caregivers did not receive enough education about their condition, even in the IRF.

...the one thing that wasn't communicated to them was I was not able to make a memory ...I kind of wish that they would (have) explained to her, my wife, that I couldn't make a memory and that's why I was having to repeat the questions and stuff like that... I kept ... asking her the same questions over and over and over again and she got tired of answering those questions....

Cole

It was common for most caregivers to drive long distances (e.g. 2–4 hours) in order to be with the person who had sustained the TBI. The vast majority of caregivers had to miss work and therefore miss paychecks. Emotional, mental and economic stresses were typical burdens for the caregivers and individuals with TBI during this phase of rehabilitation

I went back to my college days...I lived out of a backpack before, I can do it again...

Jaci, Brandon's mother

(My husband) practically moved down there at (urban location of IRF). He took a camper. We had a camper and he took a camper down and stayed....

Sybil

And they put up with me and I'd get in there about 7:00 o'clock of the morning and I didn't leave until they run me off at 6:00 or 7:00 that night...And that was every day I was in there.

Roger (Sybil's husband)

...during this critical time, the family is needed more than ever and the family is exhausted.

Cathy, Amanda's mother

Three people with TBI transitioned from acute care to other locations such as a skilled nursing facility (SNF) or long term acute care hospital. Clay was transferred to a SNF, and Clay's caregiver believed he did not receive the care he needed.

Yeah, they shipped him back down here to a nursing home instead of shipping him to (the regional IRF in urban area)... (Things were) completely out of control... they would just leave him lying there in bed (in the SNF).Where he's so young and everybody there was older and it didn't make me feel comfortable him being in the nursing home... so I just told him, I said, this ain't a place for my son, I'm bringing him home. So I had them to order me the stuff and set it up and then I brought him home and kept him with me..... So I set up that thing here (referring to the hospital bed in her living room).

Ella, Clay's mother

Brandon's mother felt that Brandon did not receive the proper care at an urban long term acute care hospital (two hours from their home). She indicated that the intravenous equipment was not well managed, and described how Brandon became dehydrated and malnourished during his stay there. He developed pressure ulcers, and she was told they would not be able to heal. Her belief was reinforced later by the fact that once she brought Brandon home, he gained weight and the pressure ulcers healed.

There were some misunderstandings about their equipment and the feeding, the tube feeding I don't think he was getting enough.... the dietitian didn't really seem to be much of an advocate for him. I would notice some of the nurses weren't doing it [tube feeding] that way (the way she was trained). So I actually said, isn't this what's supposed to be happening. So I was catching things.... Having an advocate for these people is key. You have nurses and then you change to another nurse and the shifts (change)... It is terrible for somebody in this situation.... We would've loved to see a great nursewe being all people who had loved ones there.....and for them to never be on vacation or never to take a day off until that person is well. But it cannot be that way.

Jaci, Brandon's mother

Insurance coverage was a barrier.

...we went week by week with recertification for the insurance... and just always not knowing.

Jaci, Brandon's mother

Transitioning home and reintegration into the rural community

I was (saying) every day to my nurses and doctors, I want to go home, I want to go home, can I go home, when can I go home?.... I think that I really hadn't grasped the situation that going home wasn't, wouldn't be the same.... And you know once I got home, I was like, can I go back?

Tammy

For all but one subject, home meant returning to their rural community in Kentucky. This transition was the most challenging across the continuum of care, especially for the caregivers. Many participants reported being scared of what would happen once they left the safe and structured routine of the inpatient rehabilitation settings.

Well it was....a little scary just because.... 3 days prior, I had to shower with a nurse and now I'm expected to be able to do these things either with my parents' assistance or by myself.

Murphy

Participants in this study were living in their communities with a wide variety of levels of function. Some still depended on caregivers for their daily function. Many were able to manage their own daily needs but were not able to return to meaningful activities. A few participants were involved in volunteer positions in the community. Three participants had participated in vocational rehabilitation support, but two of them had to relocate to university environments to do so, and the third felt she was humiliated in a day care/day work program and stopped participating. Participants described chronic symptoms and physical limitations that continue to affect their ability to be productive on a day to day basis even years after the initial injury. Balance deficits (resulting in falls), extremity weakness, memory disorders and slowed cognition, severe headaches, hallucinations, changes in sensory abilities (altered hearing, vision, taste), mood problems, and dizziness are examples of chronic symptoms that participants described.

The problem we run into...is his headaches...there may be 2 or 3 days a week where he can't function.

Beth, Jesse's Wife

I have knowledge for it, but I can't physically do it.

Landon

I have fell a...ton at home. But my arms are strong enough that I catch myself....And I guess my neck's strong enough where I can hold it stilland take the impact.

Bryce

Another barrier to community integration was the perceived lack of knowledge about TBI in their local communities.

Compensation sent me to him (the physician): the only thing they want him to do is just write me my prescriptions and that's it and as long as he's getting paid for it, that's all he's interested in...

Dawson

They are not used to brain injury... the equipment is not here.

Cathy, Amanda's Mother

Many of the participants traveled hours to the urban setting from their rural communities several times a week to receive outpatient rehabilitation services because they did not feel the services offered in their own rural communities were adequate.

The brain injury expertise, where is it? Well it's at (regional IRF in urban area). And that's where the neuro experienced PT's, OT's, speech; I don't know of anything beyond them.

Jaci, Brandon's Mother

Because of his mother's persistence, Brandon started receiving outpatient therapy at the regional IRF twice a week, which was a daylong process because of the distance from home and the dependence on state funded transportation.

Clay's mother and caregiver reported that Medicaid (the government insurance provider for people with low or no incomes) approved several weeks of home therapy, three times per week, but she did not believe they made significant progress in the given time period.

....they sent them here and they worked with him here.... they would (only) allow so many visits with him and they divided it up like 15 minutes to give him more time but then I was doing it all while they was here you couldn't tell (what they had done with him); I could've done that, just moved his arm, work it and everything, his feet and stuff; I could've done that because...we done it all the time anyway.

Ella, Clay's mother

Many expressed that there was a lack of knowledge and support to help them figure out how to address the financial burdens resulting from the injury.

I just gota few bills and stuff I just need to get caught up on that I can't see myself ever getting caught up on.

Nathan

The caregivers also experienced dramatic life changes. Several caregivers described taking on a new role as a nurse for their loved ones with TBI.

I never saw myself as a nurse but yet I do all kinds of things; I mean I did the wound care and you know the tube feeding and I haven't stuck anybody but that's about all I haven't done....

Jaci, Brandon's Mother

If I could hire a nurse as good as her (referring to his wife)...(there's no telling) what it would cost me.

Jesse

Several participants expressed feelings of social isolation as a result of the TBI.

People don't, they don't pay too much attention to you after, I mean, if they know you, they don't bother you.

Dawson

...really it don't bother me because I don't go...anywhere a lot. ...really I'd rather be home anyway ...the way people is; they're crazy and everything because it seems like ...they're about ready to run into you...so much meanness going on, I feel safer at home than I do getting out all the time.

Ella, Clay's Caregiver

Many stated old friends seemed to have moved on with their lives and they were unable to connect with them for various reasons such as friends' discomfort with their changed lives, communication difficulties, depression and anxiety issues, and lack of transportation.

(Before the accident) I worked 24/7 with my dad so I always had the money...I was the popular kid. Everyone wanted to hang out with me....And then when I had my accident, I can't drive now and I can't work yet so...They just, they left....I got one friend....the others I just want to beat the crap out of.

Bryce

Some expressed how living in a more urban environment would have helped the process of returning home.

(There are) so many things that would've been wonderful in an urban (area) and particularly....there would be all levels of people for her to interact with; [Amanda's].... very isolated.....the ability to interact with community on a meaningful level for my daughter...is what's the hardest part.

Cathy, Amanda's Mother

Tammy lived in her rural community for many years but just recently moved to a more urban environment. When asked if she would consider returning home to her rural community to live, she said:

Not if I could avoid it. That's why I'm really looking to get a job and, because I'm just afraid you know. That's one of my fears to have to go back home because ... there is no Wheels in... (her rural home) to take me places and if I go back home, I'll have to be (more) dependent on other people and I just don't like that....I think there's some little rinky dink cab company that (operates on) a volunteer basis and it's not much.

Tammy

Most participants were able to describe some community support, most notably when the individual initially arrived home.

...it's a real helpful community. I mean there'd be people volunteering to do stuff you know if I ever needed them to; I am confident of that.

Mary

We can't neglect, I mean I can't neglect the fact that we would be way behind the eight ball if not for our church family, people in the community; I mean people washed our clothes. They mowed our grass, took care of our pets...And money came in from.... different sources....

Jaci, Brandon's Mother

Many participants tried to voice some hopeful aspects to their outlook.

You can do what you want to do and...with the Lord on your side, then anything is possible.

Cole

A few expressed the desire to give back to others as a result of this experience. Murphy described his progression from complete dependence to independence, and his hope to support others in this process in the future.

... I was in a wheelchair and that's so humiliating, so humbling. And to think that I went from having to shower with a nurse to being so independent.... I'd speak with people and they don't, they don't understand what all I've went through. And I think of what was given back to me through therapy. To think that I could (referring to his possible future work) have that kind of impact on somebody would be the most rewarding feeling in the world....

Murphy

And I really feel...my injury, accident, I gained many things...I lost many things like my abilities and ... memory and things like that but you could focus on ... what I lost and be real upset and mad and sad but ... I also gained many things. And ... I love doing things for others. There's a whole research area looking at instead of posttraumatic stress, there's something called posttraumatic growth

Tammy

Some felt they survived for a reason:

I just feel really blessed because I realize it could've been much worse so I don't know, it just makes me appreciate being alive and ... really that's all I can think of because like at church sometimes I'll think...why did, why did the Lord let me stay...? What's the reason that I'm still here...?

Billy

Most participants and caregivers described the importance of family support or having an advocate to push you in order to overcome physical limitations.

...but when I first came out of the hospital and stuff I would have never thought about driving again...and [my wife] said, here, drive, and I did it.

Jesse

Many also recognized that those who did not appear to have as much support appeared to have poorer outcomes.

There are folks that don't have a close advocate that are, they have suffered an injury like [Brandon]'s that are in a nursing home right now all curled up.

Jaci, Brandon's Mother

Finally, when asked about utilization of existing social programs that may benefit those with TBI, only one participant was aware of the state TBI Waiver program and only two participants accessed and used the state Office of Vocational Rehabilitation.

Discussion

The purposes of this study were to increase understanding of the lived experience of people with TBI and caregivers in rural regions of Kentucky and provide their perspectives on barriers and facilitators of optimal function and well-being. Traumatic brain injury resulted in continuing challenges across the care continuum for both the individual with TBI and the caregiver, especially upon returning to their communities. Living in a rural area accentuated those challenges. Similar to the findings from Levack and colleagues [27], the people with TBI in rural Kentucky did not return to functional activities and relationships that were key to their identities prior to the injury. We found this to be true of the caregivers as well. Consistent with the findings of other studies [17,40,41,43] most of our participants had been re-hospitalized due to a variety of medical problems, and lacked meaningful activity in which to participate on a daily basis. Also consistent with previous findings were the lack of emotional support and the recurring fatigue of the caregivers [4,12,26,35]. This current study expanded our understanding by providing in-depth accounts of perspectives that represented the experiences of the individuals at each locus of care across the continuum. Even when resources such as financial support and vocational rehabilitation were available, a lack of linkages to those resources left the individuals and caregivers isolated in their rural communities.

Community integration has been defined in the literature in various ways, but all definitions emphasize that it is multi-dimensional in nature and consists of at least the components of relationships, independence in one's living situation, and meaningful activity [38,51]. These themes mirror those that emerged in our study, which were the critical role of relationships, the development of functional competence, and the challenges of finding daily meaningful activity in which to participate.

The most persistent theme was the importance of relationships and communication across the care continuum. In the early stages of emergency and acute care, communication with hospital staff is the only link to stability in an otherwise overwhelming situation. We suggest that the chaos and fear generated by communicating with multiple providers could be quelled in part by one person in the acute care setting being assigned to provide a trusting relationship and linkages among health care staff, and the person with TBI and caregivers.

Relationships with committed caregivers were lifelines for people with TBI across the continuum. Caregivers traveled to urban hospitals and IRFs resulting in many logistical challenges related to transportation, housing, and interference with employment. The availability and coordination of adequate sleeping arrangements for caregivers would substantially improve the challenges which are inevitable in a rural state such as Kentucky. Upon finally returning home, participants were often met with frustrations because of the eventual decline of relationships within the community. In some cases, connections with friends, family, and faith community eased the initial transition, but over time and in all

cases, relationships waned, and most participants felt isolated at the time of their interview. Further, most caregivers did not develop trusting relationships with local health care providers. Communication between previous IRF professionals and local rural professionals appeared to be minimal, and linkages with existing community resources were not facilitated for the transition home. This is consistent with the study by Bellon and colleagues [4] which identified the need for coordinated and accessible services as the top need expressed by those with ABI living in rural regions. A local community health worker who is trained to bridge the gap between the individual and family, and their community, could help with the important linkages families need upon returning home.

The second theme, the development of functional competence, emerged primarily after leaving acute care. There was considerable praise from participants for the staff in the urban IRF who supported individuals in the development of physical functional abilities. Participants who experienced care in a SNF or a long term acute care facility declined in terms of health and function. This highlighted the need to improve training and staffing in SNFs and long term acute care environments, or otherwise ensure that people with TBI are referred to the acute IRF. Lewis and Horn [28] found intensive rehabilitative services provided in a continuum after acute care for people with ABI (including neurorehabilitation, day treatment, and supported living) were effective in improving key areas such as self care, the ability to initiate activities, and the ability to self monitor. Positive changes in these key areas were strong predictors of reduced disability in this group [28] and positive change was seen in people who received intensive services as far out from injury as seven years. This helps dispel the myth that rehabilitation after the first year from injury is futile. Unfortunately other research indicated that many people never receive or receive too little rehabilitation after TBI [18,29,32]. Our observations were that after acute inpatient rehabilitation, intensive rehabilitative services were uncommon, particularly after the first year from injury.

The transition to home was a critical time for all participants and most experienced substantial obstacles to functional competence. Solovieva and Martin [46] and Bellon [4] demonstrated that knowledge of available resources and ability to access them remain substantial challenges for those with TBI living in rural areas, and this was true for our participants. They had recurring health problems and settled for a vulnerable homeostasis, often employing coping mechanisms that helped in the short term but contributed to long term problems. Caregivers also felt ill prepared and exhausted by the time of this transition. Education for caregivers was not adequate in most cases to result in the transfer of functional skills learned in the IRF or SNF to the home environment. The physical adaptations of the house and the mountainous land presented challenges, and there was very little money or expertise to make needed adaptations. Transportation was a challenge.

Two key resources available in Kentucky for people with TBI are Medicaid waiver monies and the Kentucky Traumatic Brain Injury Trust Fund. Medicaid is the federal health insurance program in the US for people requiring financial assistance. Medicaid waiver programs have been established in many states, including Kentucky, to permit Medicaid money for support services to a limited number of people in need, including those with TBI [1]. The Kentucky Traumatic Brain Injury Trust Fund was established through a tax on fines

for Driving Under the Influence charges, and limited resources can be accessed through this source as well [45]. While the programs have limitations, they can be quite beneficial to people with TBI. It is disturbing that only one person in our study indicated utilization of these resources. Most participants with TBI had little meaningful activity in which to participate. The Office of Vocational Rehabilitation (OVR) is charged with helping people with disabilities find employment [19]. The full services of OVR had only been accessed by the two individuals who were pursuing graduate degrees. This may be an area to explore in the future to better connect the appropriate TBI population with this program.

According to one systematic review, there was limited but consistent evidence that case management improved linkages to community services, vocational outcome, and life satisfaction for people with TBI [24]. Researchers examining case management services for people with TBI reported positive outcomes in functional competence, independence, and social networking [8,30]. Baptiste and colleagues[2]summarized the research supporting the effectiveness of case management in life care planning for those with TBI, and found that people with TBI who live in institutional settings or group homes are more likely to use case management services than those who live alone. The participants in this study were relatively isolated and lived in rural areas where case management services appeared inaccessible or unavailable.

Espinosa [16] demonstrated the fiscal effectiveness and the improvement in quality of life for people with varying diagnoses, including TBI, who received case management services in Kentucky. Researchers have also demonstrated the positive outcomes of telephone follow up by case managers with veterans with service related TBIs living at home [30]. The use of telecommunications for case management follow up for people in rural Kentucky is a model worth exploring.

We propose the expansion of professional case management resources for people with TBI, with contact occurring as soon as possible after the injury and continuing across the care environments. While this type of system is available in some countries (e.g. [2,8,24])and in some urban areas in the United States (e.g. [28]), it is missing in rural regions, likely due in part to the challenges inherent in linking professional case managers to patients in rural areas. One approach to address this issue is to have the professional case management services be made available during the acute and subacute phases, with a transition to a community health worker (i.e lay health navigator) who lives in the rural region to which the individual is returning. The efficacy of using local health navigators has been and is continuing to be explored in the area of cancer care and stroke, with positive outcomes for reduced hospitalization and improved health outcomes [14,34]. Such a lay health navigator/ community worker does not necessarily need to be a health care professional but rather a person with adequate training about the needs of people with TBI and a broad understanding of available local resources. The professional case manager could provide leadership and support to the local health navigator (and the clients), as needed, through the use of telecommunications. Furthermore, the local health navigator could provide linkages among those in the region with TBI, and caregivers, facilitating a peer support network which has been shown to be helpful in providing emotional and informational support [4]. We hypothesize that such an expansion relying on professional case management in the early

stages of care and trained lay health navigators in later stages would reduce costs in the long run and contribute to the well-being of people with TBI and their caregivers.

Study Limitations

This study was designed to provide in-depth information about the lives of people with TBI and their caregivers, living in rural Kentucky. As such it was limited to a small sample size in one predominately rural state in the United States. Generalizations to people with TBI in other rural areas of the country should be made with caution. In addition, interviews with the caregiver were sometimes completed in the presence of the person with TBI or another family member, and this may have influenced their responses. While we cannot be sure of what type of differences may have occurred due to interviewing some dyads, the perception of the interviewers was that the participants were extremely forthcoming. For people who were interviewed as dyads, there was more of a likelihood that those people with TBI had more severe injuries. By having their caregiver take part with them they were provided support and helped to express their own views. There was a likely a sampling bias because the people who responded to the flyer were those who were motivated to tell their story and/or had a caregiver with similar motivation. Future studies should focus on people in rural areas of other states and countries, to determine if the narratives are similar, especially in countries with differing systems of health care provision.

Summary

This study provided detailed perspectives on the barriers and facilitators of optimal functioning across the care continuum from rural Kentuckians with TBI and caregivers. Their experiences in survival were fraught with unpredictable outcomes due in part to the continuing changes over time. Caregivers faced unique challenges. Unmet needs were most pervasive when participants were adapting to life in their rural communities. We propose that case managers who understand needs specific to people with TBI and caregivers could provide service coordination early and across the continuum, and trained community health workers who live within the local community might be able to extend that case management support when the individual returns home. This would hopefully provide trusted relationships throughout the continuum of care and improve linkages to services that facilitate continued development of functional competence upon returning home. Additional research to examine the efficacy of case management and community health worker support for people with TBI living in rural areas is warranted. We observed a remarkably hopeful outlook in many caregivers and people with TBI, suggesting a foundation for constructive use of resources and supports, if available and accessible.

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Appendix A

Interview guide: Individual and caregiver*

1. Describe the experience of having the TBI.
2. Tell me about transitions between each location of care, and the transition home.
3. Tell me about any rehabilitation (e.g. PT, OT, Speech therapists) you (or the person for whom you care) had?
4. *(If not answered in previous)* What sort of rehabilitation has occurred since you have been home?
5. Could you describe any complications since the TBI (question is for caregiver and person with TBI)?
6. How and where do you get medical or other care when needed since the TBI?
7. How do you spend a typical day? What are your biggest problems since the TBI in terms of functioning, getting around, taking care of yourself or your loved one?

8. What is the hardest thing and the best thing about living in your community in terms of the TBI?
9. Do you feel your family members (or extended family or other caregivers) were prepared to help you?
10. *(If not yet addressed)* Does someone help you make decisions about your care/health (person, family, doctors...)

For caregiver only (in addition to the above questions as appropriate):

- Do you feel you have the resources you need to adequately help and support your relative/loved one/ person for whom you care, in his/her own home?
If yes, describe the key things that allow you to do that?
If no, describe what you need to better support the individual in his/her home and community?
- Have the health care providers helped you understand useful ways to help your relative/loved one/ person for whom you care?
- Are there any other issues you feel either help or hurt your well being in terms of the TBI?

(For both)

I am going to give you part of a sentence and would like you to finish it:

Living with brain injury is like _____

*Probes for each question and demographic questions are not included in this appendix.

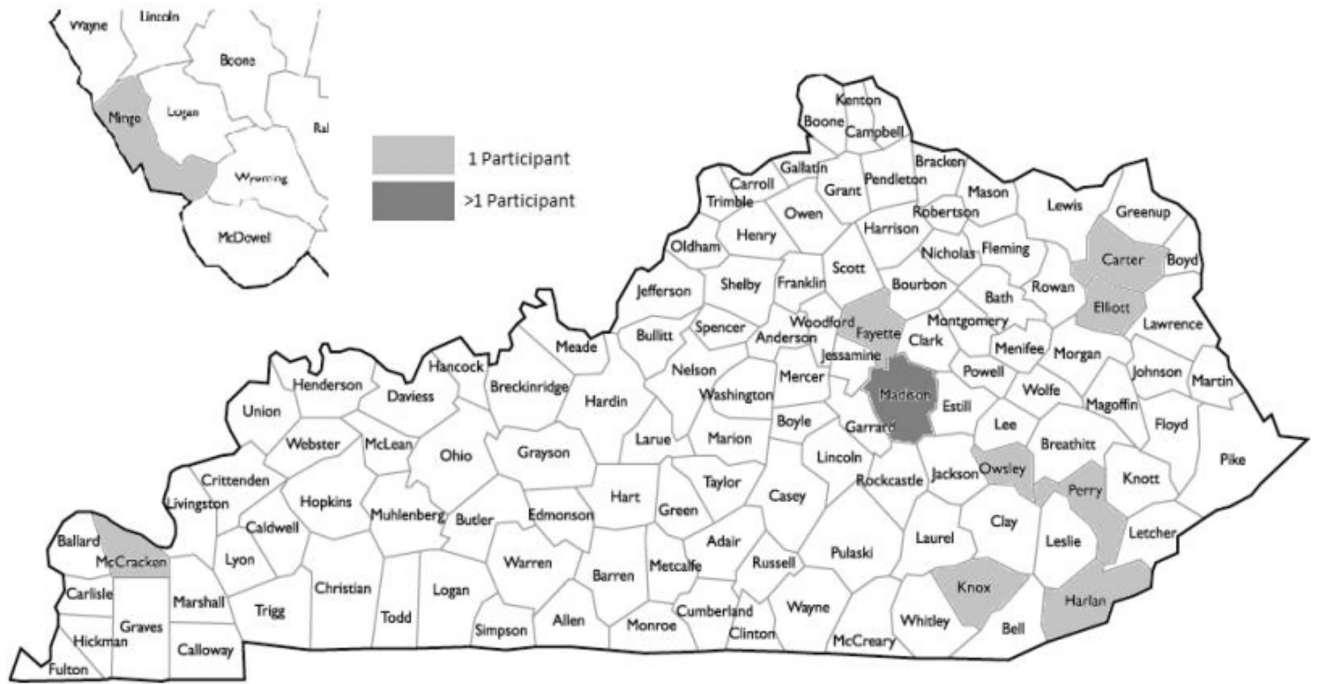


Figure 1.
Counties of residence of participants interviewed

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Table 1

Demographic Data Summary

	Gender	Age (years)	Level of Education	Employed?	Household Annual Income	Years Post-TBI
Participants	Males: 10 (76.9%)	Mean: 36.8	Below HS [*] : 5 (38.4%)	Yes: 0 (0%)	< 15,000 : 1 (7.7%)	Mean: 6.64
With TBI	Females: 3 (23.1%)	Range: 20–56	HS: 1 (7.7%)	No: 11 (84.6%)	15,000–20,000: 1 (7.7%)	Range: 1–18
(13 Total)			College: 5 (38.4%)	School: 2 (15.4%)	21,000–35,000 1 (7.7%)	
			Unknown ^{**} : 2 (15.4%)		36,000–50,000: 3 (23.1%)	
					50,000–65,000: 0 (0%)	
					> 65,000: 2 (15.4%)	
					Unknown ^{**} : 5 (38.4%)	
Caregivers						
(6 Total)	Males: 2 (33.3%)	Mean: 54	Below HS: 1 (16.7%)	Yes: 3 (50%)		
	Females: 4 (66.7%)	Range: 49–58	HS: 1 (16.7%)	No: 3 (50%)		
			College: 2 (33.3%)			
			Unknown ^{**} : 2 (33.3%)			

* High School

** Missing data; participant chose not to provide

Table 2

Participant code names and characteristics

Participant	Gender	Age (yrs)	Caregivers interviewed	Time since injury, approximate (yrs)	Mechanism of Injury
Brandon	M	20	Iaci (mother)	1	Motor vehicle accident
Amanda	F	32	Cathy (mother)	5	Motor vehicle accident
Tammy	F	29		11	Motor vehicle accident
Jesse	M	42	Beth (wife)	6	Self-inflicted gunshot wound to head
Mary	F	56	Billy (husband)	5	Motor vehicle accident
Cole	M	52		5	Motor vehicle accident
Clay	M	36	Ella (mother)	7	Motor vehicle accident
Nathan	M	49		7	Motor vehicle accident
Dawson	M	55		9	Motor vehicle accident (driving heavy machinery)
Bryce	M	20		2	Motor vehicle accident (motorcycle)
Sybil	F	56	Roger (husband)	7	Motor vehicle accident
Landon	M	42		5	Brain tumor with surgical trauma
Murphy	M	23		5	Motor vehicle accident