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Abstract

Title: Care coordination experiences of people with traumatic brain injury and their family members 4-years after injury: A qualitative analysis

Aim: To explore experiences of care coordination in the first 4-years after severe traumatic brain injury (TBI).

Methods: A qualitative study nested within a population-based longitudinal cohort study. Eighteen semi-structured telephone interviews were conducted 48-months post-injury with six adults living with severe TBI and the family members of 12 other adults living with severe TBI. Participants were identified through purposive sampling from the Victorian State Trauma Registry. A thematic analysis was undertaken.

Results: No person with TBI or their family member reported a case manager or care coordinator were involved in assisting with all aspects of their care. Many people with severe TBI experienced ineffective care coordination resulting in difficulty accessing services, variable quality in the timing, efficiency and appropriateness of services, an absence of regular progress evaluations and collaboratively formulated long-term plans. Some family members attempted to fill gaps in care, often without success. In contrast, effective care coordination was reported by one family member who advocated for services, closely monitored their relative, and effectively facilitated communication between services providers.

Conclusion:

Given the high cost, complexity and long-term nature of TBI recovery, more effective care coordination is required to consistently meet the needs of people with severe TBI.

Keywords: Traumatic Brain Injury; care coordination; health literacy, community;
interviews; qualitative

Introduction

The consequences of severe traumatic brain injury (TBI) can be devastating and lifelong. Diverse physical, cognitive, behavioural and social outcomes typically require specialised and ongoing management [1]. The quality and comprehensiveness of the services received, however, can depend on multiple factors. The health literacy of the person with a TBI and their family members can affect their knowledge of their health condition and navigation of the health system [2]. The quality of communication between health professionals providing treatment and other health professionals involved in a person's care can impact on the quality of care received [3]. Insurance or public healthcare funding and the availability of services needed after a TBI can influence access to care, as can living in a metropolitan or regional area [4; 5]. The capacity of a person with a severe TBI to manage their own care is also important for service access [6]. Given these complexities, effective care coordination can positively impact the recovery and health outcomes of people with severe TBI [7].

Care coordination for people with chronic and disabling health issues can be delivered in numerous ways, as varying models of care coordination exist [8; 9]. However, most agree that care coordination activities include communication to exchange information between service providers and the patient, facilitating transitions between services, linking resources, proactive planning, monitoring and assessment to identify and address needs, and coordinating follow-up with the patient and services [10]. In Australia care coordination faces added complexity with the state government administering hospital care and the commonwealth government directing primary care [11]. This funding system has created varying clinical models for care coordination. Typically, hospital-based care coordinators are

dedicated health professionals who support patients' transition from hospital-based care to the community, especially in complex specialty services providing care for cancer, mental health, and other chronic health conditions [11; 12]. In the community setting, however, people with long-term care coordination needs could receive coordinated care from a general practitioner (GP) or another trained community-based health professional, such as an advanced practice nurse or allied health professional. Such services are privately available and publicly funded for some [11].

While the cost of a private care coordinator will be unaffordable for many, it is not the only barrier to care coordination in the community. Fragmentation of the health system, disconnected health information technology systems, insufficient time, and inadequate specialist knowledge can all negatively affect care coordination activities [3; 13-15].

Additionally, inequitable access to services, difficulty implementing team meetings, and multiple transitions in care, all contribute to ineffective care coordination [12]. However, when effectively implemented, the benefits of care coordination in the management of chronic diseases are well-recognised [16-18]. Care coordination can promote timely access and engagement with appropriate services based on individual needs, improve quality of care and the flow of information, as well as enable cost savings [3; 8; 10; 19]. Given the high economic burden of TBI, and that people with TBI report the need for greater supports when transitioning home and when living in the community [20-22], detailed insights into these issues can be gained through qualitatively exploring care coordination.

In the years following injury, people with severe TBI have many unmet and ongoing needs [21; 23-25], high service use [23; 25; 26], high claims through insurance agencies [26] and

significant costs associated with the delivery of services [23; 26]. McCluskey et al. found that case managers who provided coordinated care could promote independence, freedom, and autonomy in people with TBI [27]. Ownsworth et al. suggested people with TBI would benefit from care coordination assistance, as few services specialise in long-term community based care for people with acquired brain injury [24]. Ultimately, as management of people with TBI often entails dealing with multiple, shifting and complex issues [21; 23; 24], a well-coordinated response has the potential to result in optimal outcomes [17]. Therefore, the aim of this study was to explore experiences of care coordination in the first four years after severe TBI.

Methods

Setting and participants

The Victorian State Trauma Registry (VSTR) is a population based registry which captures data about all major trauma patients in Victoria, Australia. It is used to monitor the performance and effectiveness of the Victorian trauma system. All eligible cases are included on the registry unless they choose not to take part. Data are received from treating hospitals and held by the registry including demographics, injury incident information, pre-hospital and hospital details. Information, including pain, function, work, and health-related quality of life are collected by trained VSTR interviewers at six, 12, and 24 months post-injury [28].

The RESTORE (REcovery after Serious Trauma—Outcomes, Resource use and patient Experiences) is a population-based longitudinal cohort study with a nested qualitative component. The project aims to explore the long-term outcomes (up to five years post-

injury) and the recovery experiences of seriously injured people [29]. To address this aim, individual interviews were selected to enable participants to speak freely about their experiences and perceptions [30; 31]. Participants with a date of injury from 1 July 2011 to 30 June 2012, who survived to hospital discharge, and had not withdrawn their consent to be part of the VSTR were included. The Monash University Human Research Ethics Committee and participating hospitals approved the project.

This exploratory qualitative study focuses on RESTORE participants who were aged 16 or older at the time of injury and had a severe TBI. Severe TBI cases were initially identified by a maximum head Abbreviated Injury Scale (AIS) score of three or higher (using the AIS 2005-2008 update) and a Glasgow Coma Scale (GCS) score of three to eight [32; 33] on arrival at the first hospital that the patient was transported to. If this was unavailable, the pre-hospital GCS score was used, as recorded by the pre-hospital service.

Access to health care can be affected by the mechanism of injury. In Victoria, the Transport Accident Commission (TAC) or WorkSafe Victoria are the no-fault third party insurers for road transport and work-related injuries. For people who sustain a severe TBI, injury insurers can provide compensation for medical services and rehabilitation regardless of fault and for as long as the need is clinically justified [34]. Loss of earning capacity payments can provide income replacement until retirement age (usually 65 years) in individuals assessed to have greater than 50% impairment. For people with permanent physical and psychological conditions, a one off 'impairment benefit' can be paid in addition to income support and medical services [35]. Lifetime supports including payment for supported accommodation, formal carers and/or supported community services that are planned with

the insurer and are subject to periodical review. For those severely injured at work, the claim is often managed by TAC due to their experience with supporting people with serious injuries. Early Support Coordinators (ESC) at the TAC are allocated to compensable clients to be the key contact at the organisation, provide information about support offered, and to manage claims by making decisions on requests for treatment and services [36]. In the event of a crisis or emergency, Intensive Support Coordinators are available for short-term assistance. People with non-compensable injuries are covered by Australia's publicly funded health care system (Medicare) and may need to wait for funding for access to services and supports unless they have purchased private health insurance [37].

Data collection and analysis

Adult survivors followed-up to 48 months post-injury who had consented to an in-depth telephone interview were purposively sampled based on their age, gender, compensation status (yes/no), residential location (metropolitan or regional), and whether their care was delivered at a major trauma service or not (yes/no). This technique ensures representation from each of these categories in the final sample [38]. To answer the research question using purposive sampling, it was estimated 15-20 interviews would be required. A proxy (a caregiver closely involved with the person with a TBI) was asked to take part if the participant had cognitive or memory deficits likely to make the interview process difficult (as assessed by the person closely involved). Non-English speaking people were excluded from the study as resource constraints did not allow for the use of interpreters. This excluded approximately 8% of people registered with the VSTR from participating in the study. As part of the consent process, participants were informed about the interview topics

that would be discussed. All participants consented to recording and transcription of the interviews.

Semi-structured telephone interviews with individual participants took place between July 2015 and June 2016 and involved a median interview time of 47 minutes. After 18 interviews, no new information was arising and the decision was made to stop recruitment. Three experienced interviewers trained in qualitative interviewing techniques performed the interviews. Two (a male and a female) were psychology graduates (non-clinical), and one was a female research officer who had previously worked as a nurse. A semi-structured topic guide was used to direct each interview, which covered the following:

- the treatment and services received;
- what (if anything) could be improved;
- who was involved in delivering care;
- perceptions of communication with and between service providers;
- current needs and if they were being met (and if not, why not);
- experiences with insurers;
- what helped and hindered their recovery.

Probes were used by the interviewers to encourage more detailed description as required.

A framework approach was applied to perform a thematic analysis [39]. To manage the data, transcripts were loaded into, and coded in, NVivo 10 (QSR International, Doncaster). The first author and a research assistant (also one of the interviewers) trained in NVivo completed the analysis. The process was iterative and inductive. Initially, the transcripts were read in their entirety, and notes about the content and meaning were made

throughout the transcripts. Patterns and repetition in the data formed broad themes. The final themes and subthemes created a framework of inter-related connections and patterns [39].

A reflexive stance was maintained throughout data collection and the analysis process. To enhance rigor, detailed records were kept, and regular debriefs, peer review, and negative case analysis were conducted [40]. A record of analytic and methodological decisions was kept for the project duration. Regular meetings and debriefings between the three interviewers and the project manager as a group enabled discussion about potential biases and if particular outcomes were anticipated. While no known biases were declared, in-depth discussions involved revisiting interpretations and alternative explanations, enhancing trustworthiness of the analysis [40]. Detailed records of coding and theme development decisions and negative case analysis (examination of data that did not support interpretations) reflected a collegial relationship between the first author and the research assistant. Both regularly raised questions about each other's coding, and in all circumstances mutual agreement was reached. For example, many of the final themes reflected neither of the coders' original suggestions, but jointly agreed upon content. Presentations of developing analysis to the interviewers and the broader investigative project team, assisted with reflection on and development of the framework.

Results

Eighteen interviews were conducted at 48 months post-injury with six people living with severe TBI and the family members of 12 other people living with severe TBI (a parent,

spouse or sibling of the injured person). Most people with TBI were male and injured in road traffic crashes. Over half were compensable, and more than two thirds lived in a major city. Five reported a mild, and one a moderate, pre-injury disability. At 48 months post-injury, most individuals with TBI in the study (86%) had moderate to severe functional disability. The profile of the participants is shown in Table 1.

Of the 18 people with severe TBI, all were engaged with service providers four years post-injury, with a mean of 3.2 (SD 2.5) and a range of 1-12 care services per person over one year. These services were used for the specific treatment and management of TBI, as well as for other injuries sustained. Most described predominately engaging with GPs, physiotherapists, psychologists, medical and surgical specialists, as well as other service providers. No person with TBI had a dedicated case manager or care coordinator. While 12 people with TBI were compensable and referred to an ESC in the years after injury, four years after injury, only four participants reported an active ESC. Formally appointed ESCs were described by people with TBI and their family members as 'gatekeepers' who controlled access to services by being responsible for approving funds. No ESC was referred to as a key coordinator of health and service needs for people with TBI.

Figure 1 is a thematic map that shows the relationship of the subthemes with effective and ineffective care coordination. The middle boxes show the components of care coordination identified by participants. These components had the potential to lead to effective or ineffective care coordination based on the context stated on the arrows. The arrows leading from effective and ineffective care coordination boxes show the possible outcomes.

Variable engagement with service providers

Empowering interactions

Some people with TBI and their family members perceived positive engagement with service providers empowered them with knowledge and promoted understanding and effective decision making. Positive service provider qualities that were highly valued included being knowledgeable about severe TBI, displaying empathy and understanding, and having patience and excellent communication skills. These qualities were reported as frequently displayed by medical specialists and psychologists:

The psychologist, he's really, really good...specialises with brain injury. He's actually a very friendly person. I get along with him really, really well. I really have no flaws with him.... It might just be the friendly behaviour. He doesn't try to be high powered... He seems to come across more like a level playing field (*Male_16-39yrs_metro_non-compensable_head injuries and spinal fractures*)

Unproductive interactions

In contrast, some people with TBI and family members expressed difficulties and challenges when engaging with service providers. This was mainly experienced with GPs, but issues extended to other allied health professionals. Unproductive interactions were described as communications that failed to address issues of concern to the patient and the family, such as headaches, other pain, balance, behavioural, and mobility issues, resulting in variable quality of care:

He doesn't like to see the doctor at all.... The problem is the doctor (GP) always asks the same questions. (Name of person with TBI) says before you ask, 'I can answer you now'.

(The GP) sometimes says, 'Did you sleep well last night?'

He (the person with TBI) say, 'Yes'.

(The GP asks), 'You eat well last night?'

(The person with TBI) say, 'Yes'.

Only that.... Physically, he needs more training. Like balancing himself when he stands... His brain can't control his balance....and he walks like an 80 years old man.

(Male_16-39yrs_metro_compensable_head, and multiple other injuries_proxy interview)

Roles and responsibilities in care coordination

Effective care coordination

While care coordination activities were reported by most people with TBI and family members to be ineffective, there was one exception where a family member effectively acted as the key coordinator for her relative's care. Effective care coordination was demonstrated by her advocating for appropriate care services, promptly responding to issues, communicating with all the service providers, and changing care team members to best meet her relative's needs:

I'm more about what's important for my [name of relative]. I understand that there are protocols and I understand that there is funding and all of that sort of stuff, but I

want to be able to understand what's best for my [name of relative] and that a regime needs to be formed around him and he doesn't need to fit into a clinical regime or whatever it happens to be. So, if someone takes on a client then you need to be able to meet their needs, not fit the client into your existing regime. I think that was the biggest factor in making that change. *(Male_16-39yrs_metro_compensable_head injuries_proxy interview)*

Access to care

Issues of importance to people with TBI were usually first reported to GPs. People with TBI and family members expected GPs to link the person with TBI to other appropriate services. While many GPs performed this vital care coordination activity, some failed to provide advice or take action to arrange referrals. Failure to address perceived issues resulted in persistent and unmet needs such as headaches, other pain, social problems and behavioural issues. It also made it more difficult for people with TBI and family members to access desired services:

He has really bad headaches and he has never had another scan done since the injury, which bothers me, with the severe headaches he gets. It's really difficult when you go to a doctor (GP), they kind of just shrug their shoulders. When I've asked for certain things they just kind of just don't ... they're not getting the whole picture, they don't have him around 24 hours, so... they just don't seem to take things seriously. And to me it is a very serious matter... They just shrug it off, they just avoid it... they just quickly write a script and you're out. *(Male_16-39yrs_metro_non-compensable_head injuries_proxy interview)*

Consulting individual service providers

Most people with TBI received care from multiple service providers who worked independently and in parallel with each other. While, for some, their GP or a rehabilitation specialist may have referred the person with TBI to other services, this referring doctor did not always have awareness of, or communication with, all of the other service providers involved in their patient's care. Indeed, no person with TBI or family member described a GP (or any other service provider or ESC) as a key coordinator who linked the person with TBI to, and communicated with, all the service providers involved in care delivery. However, many expressed the desire for a service provider to take on this role:

I see my GP every couple of weeks, but my rehab specialist not a great deal.... I acquired diabetes and epilepsy from the head injuries... I'm always seeing doctors, dieticians etc ... Every now and then I go and see the psych, but generally I've been left to my own devices.... If I can get my physio back up and running (previously provided by insurer), I'm quite sure I'd be a lot better ... something as simple as a regular appointment with the specialist would be a help because then they'd be able to keep tabs on what was going on. The system's not that great. I've just learnt to deal with it. *(Male_16-39yrs_metro_compensable_head_injuries)*

Service suitability and quality

Some people with TBI and family members perceived services to be ineffective, and described no one being accountable for ensuring services delivered what they were employed to do. They felt that without a key coordinator to take overall responsibility, there was an absence of regular progress evaluations and forums to report service provider

inaction or to detect a lack of progress. Family members noted behavioural and social issues, physical function and strength, memory, as well as independent living skills, to be areas that all required greater attention and effective intervention to meet the ongoing needs of people with TBI.

(Name of person with TBI) is supposed to have a social worker but the social worker is not very active... when we have a meeting there is a list of things that say will be done, but they never get done, and that includes trying to help (name of person with severe TBI) socialise in the community...but she doesn't have any other activities apart from medical appointments... *(Female_16-39yrs_regional_compensable_head injuries and multiple fractures-proxy interview)*

When the family member above was asked how the situation could be improved, she replied that more frequent evaluations and team meetings could better address the unmet needs of her daughter. Additionally, it was suggested that collaboratively formulated rehabilitation plans were needed to build daily living skills:

Just being there a bit more often. Being there for her in various situations that she's been ... just possibly get together a bit more (the treating team) and understand how she is and what her needs are.... They (service providers) don't seem to have any strategies for her, they just think she's able to look after herself in that way, but she does need strategies and she does need advice...I would have liked more help with organising her daily activities. *(Female_16-39yrs_regional_compensable_head injuries and multiple fractures-proxy interview)*

Family support

Watching and supporting

An important activity assumed by family members was watching the person with TBI for changes to ensure their needs were detected and promptly addressed. Most family members reported that this role was rarely performed by a service provider. Some people with TBI self-monitored, but most often family members described closely watching their relative. Family members provided advice to people with TBI, or attempted to advocate on their behalf, but felt they had little success as they struggled to navigate complex systems (such as health, disability and compensation):

We're not really advised. You've got to search things out yourself for her... So when she is battling along and you notice a change... you don't have any direction for what to do when, like who to go to. *(Female_16-39yrs_metro_compensable_head injuries and multiple fractures-proxy interview)*

Taking action

While most family members provided vital practical support to assist their relatives with managing their health (such as driving to medical appointments, paying for medications), one family member was the key coordinator for her relative's care team. Highly health literate, this family member had detailed knowledge of each service's role and her relative's needs, took action to link and organise service providers, and facilitated communication and collaboration between services. The family member also described gathering information to make informed decisions, advocate, and initiate changes to the team to ensure the goals of care delivery were aligned:

So in the last 12 months, I've reviewed all of the treating team, the people that work with them (staff in supported residence) in that we have choice. So the people that

work with them have been chosen by myself. So I kept most of the treating team and we just made changes with the occupational therapist, because... I sometimes felt that we weren't coming from the same page in relation to (name of person with severe TBI) needs.... (*Male_16-39yrs_metro_compensable_head_injuries_proxy interview*)

Funding for services

Insurer directed management

Twelve people with TBI relied on their insurer to deliver services for their recovery; yet, they felt that insurers sometimes made care coordination more complex by creating barriers to service provision. Many people with TBI and family members expressed frustration with the frequency of ESCs changes in the first four years after injury, which made communication with someone knowledgeable about their case difficult, and that authorisation for services could be slow and sometimes not provided. While some were satisfied with the services supplied by their insurer, others identified unmet needs for services such as psychology, physiotherapy, pain management, occupational therapy, carer, social work, and career planning. Furthermore, at times the frequency of a provided service was reported to be inadequate. A number of people with TBI and family members described previous unsuccessful attempts to reverse decisions made by ESCs:

The pain is exacerbated because I'm not having the physio.... Work cover has pulled the pin on me, so I'm not really getting anything as far as concerning physio and all that. My (name of specialist doctor) is trying to organise some more now but the

amount of red tape they put me through, half the time I sort of just give up and just put up with the pain. (*Male_16-39yrs_metro_compensable_head_injuries*)

Restricted and regulated funding

Funding provided by insurance and government agencies for services was perceived as being limited and therefore lasted for short periods. Many people with TBI and family members described services stopping abruptly without reassessment and despite ongoing needs. Ultimately, those with adequate health literacy, the capacity to self-fund, or the ability to strongly advocate, largely received ongoing treatments:

A couple of people come on board in the beginning and it was short lived because of funding... and then we're just left to deal with it. And I think that's really unfair. I think the system sucks. It lets people down and (name of son with TBI) has always seemed to fall through the cracks.... I find it frustrating... all they would say was 'We're finishing up next week because the funding has run out.'... We were told in the beginning that we would have a case manager on board. He came out twice to the house and we never saw him again... and so (name of person with TBI) hasn't had any help or anything for years now, so he battles a lot with a lot of things that go on. (*Male_16-39yrs_metro_non-compensable_head_injuries_proxy interview*)

Discussion

The results of our study provide valuable insights into the experiences of care coordination for people with severe TBI and their family members in the first four years after injury, in

the context of a no-fault accident compensation system providing funded services to some people injured in motor vehicle crashes or in the workplace. The findings highlight that some care coordination activities successfully took place, such as useful communication interactions and close monitoring by family members. However, it was also clear that many people with severe TBI experienced ineffective care coordination resulting in difficulty accessing services, variable quality in the timing, efficiency and appropriateness of services, insufficient evaluation of services, and a lack of collaboratively formulated long-term plans. Overall, a lack of care coordination activities and the absence of a key coordinator increased the challenge of meeting the individual and complex needs of people with severe TBI.

Our findings highlight that no key person coordinated long-term care, and/or issues existed with care coordination activities. In the absence of an accountable key coordinator, long-term planning, information sharing, and the alignment of needs with resources, did not consistently transpire. Many people with severe TBI lack the decision making ability and memory to independently navigate complex information and services in health, compensation and disability systems [27]. Some also live with comorbid physical and mental health conditions increasing the complexity of their needs [41]. In our study, family members attempted to fill gaps in care by advocating, watching, providing practical support, attending meetings, and making suggestions to health professionals. This sometimes frustrating and time-consuming work can add burden to a carer's role, increasing psychological distress, reducing the carer's quality of life, and adversely affecting the quality of the relationship between the carer and person with a TBI [42-44]. Carers of people with severe TBI are also at risk of mental health issues such as anxiety and depression for many years after injury [44; 45]. Effective care coordination is therefore not only important for

people with TBI to receive quality and planned care that meets their needs and goals, it is also important for preventing extra stress on family caregivers [46].

People with TBI and family members described difficulty navigating health systems, particularly when GPs had not provided the advice or coordination of care expected. To assist people with TBI and their family members with navigating the health system, improved health literacy could support positive health actions for recovery. As health literacy skills involve obtaining and understanding information and using it for effective health decisions, it is important for equity and access to appropriate services [47]. Targeted efforts to improve individual and family member health literacy, such as building confidence for engagement and advocacy with service providers [48], could encourage greater care coordination activity. Further, reducing health literacy barriers in the recovery environment, such as providing information in videos, through a telephone support line, or checking the readability of printed information, could support better communication with health professionals and more effective care coordination [17; 49]. Health professionals, insurers, and community-based organisations that provide information and services all have a role in building health literacy skills, and in reducing the complex health literacy environment (e.g., printed information, advice given).

Linking people with TBI and their family members to others that have experience with recovery from severe TBI could also empower people with knowledge about care coordination. Peer support and support groups that provide social support, promote resilience, coping strategies and adaptation, and the sharing of ideas, could foster a better understanding of how to commence, participate in, and sustain effective care coordination

[50]. While community-based organisations can coordinate peer support programs and support group meetings, such supports should be adjunct to a dedicated care coordinator.

People with severe TBI are a heterogeneous and highly individualised population that have high service usage for years after their injury, but continue to experience ongoing and evolving needs [21; 23]. In our study and others, unmet needs were identified in the areas of behaviour management, social skills, physical strength and function, memory, and independent living skills [21; 51]. Further, despite the benefits of timely detection and specialist management of problems, regular assessment, aligned treatment goals, and proactive care plans [3; 8; 49], these care coordination activities were largely absent in our study (regardless of the person's compensable status). Previous research confirms that a lack of care coordination activities can result in unmet needs, the occurrence of preventable conditions, and poor progress or deterioration in recovery [27; 49], as observed in our cohort. Given the effectiveness of formal key coordinators for people with chronic diseases, a coordinator knowledgeable about severe TBI, and funded independently of an injury insurer, could offer similar benefits to people with TBI and their families [16-18; 27]. Key coordinators can facilitate communication and collaboration between multidisciplinary service providers to develop a shared awareness of new and evolving issues to identify appropriate and timely service intervention [18; 27; 51]. Follow-up by a key coordinator over an extended time period could optimise care by early identification of those not coping, initiating timely support and assessments, and liaising with insurers, services providers, the person with TBI and/or their family to individualise care pathways [18; 27; 51].

In our study, people with severe TBI and family members described variable communication quality in their engagement with service providers. While some were very satisfied, others reported unproductive and disempowering interactions (particularly with GPs) when vital care coordination activities were not carried out. While most people with TBI consulted GPs, the latter were not described as proactive managers or key coordinators of all the service providers involved in their care. While GPs have an important role in providing community-based care, barriers have been previously reported that prevent GPs from performing care coordination. A lack of TBI or disability specific knowledge, insufficient skills and resources for managing complex cases, and short appointment times have all been identified [3; 24; 52].

To effectively coordinate care, GPs require adequate reimbursement for coordination activities that require longer appointment times, and access to linked electronic medical records that support direct communication, referrals and care integration [15]. While education in long-term TBI care management has the potential to support and build capacity in GPs to better understand the needs of people with severe TBI, there is a need to build more sustainable models of care coordination [3; 15; 23]. As GPs are often required to coordinate both community and hospital based services, a hospital GP liaison service could assist with system issues to improve the delivery of patient care. An alternative approach could involve specialist TBI service providers, such as advance practice nurses, taking on the role as key coordinators [15]. Additionally, models of care such as the 'patient-centred medical home' that have been implemented in the US and Canada could potentially improve community-based care coordination [53]. In this model, care coordination is undertaken using a team-based, patient-centred approach, as multiple health professionals

(e.g., GPs, physiotherapists, occupational therapists) collaborate as a centralised source of care [53]. Furthermore, drawing on learnings from the United Kingdom and New Zealand, establishing an organisation that has the authority and responsibility for developing care coordination across hospital and community sectors could lead to reform in this area in Australia [11].

For people with severe TBI who were compensable, accessing services through insurers added a layer of complexity to receiving effective care coordination [54]. Many people with TBI and their family members expressed frustrations and difficulty achieving long-term progress. It is possible that convoluted organisational policies and procedures, complex information systems, and low health literacy with respect to insurance systems, were barriers to service access and continuity, and therefore care coordination [54]. It is also possible that some people had a lowered tolerance for dealing with bureaucratic systems after four years of engagement [6]. The provision of independent care coordinator paid for by the government, could improve equity, service access, timely service use, and reduce the frustrations for all people with severe TBI and their families (not just people who were compensable) [18; 27]. These benefits could be justified by the cost savings gained from effective care coordination, such as reducing service duplication and leveraging services to provide more timely, effective, and quality care [3; 8; 49].

For injured people not eligible for compensation, the Australian government recently launched a \$22 billion National Disability Insurance Scheme (NDIS) for people aged under 65 years who experience significant and permanent disability [55]. While not fully implemented, the NDIS aims to provide reasonable and necessary supports relating to

disability, which may include the provision of support coordination for a limited time in a crisis. While support coordination is likely to benefit people with severe TBI who use long-term community based supports, the findings from our study suggest the need for more continuous care coordination activity.

Limitations

This study offers detailed insights into how care was managed for 18 people with severe TBI in the first four years after injury in a mature trauma system. It is important to note that this study focuses on the perceptions of care coordination from the perspective of people living with TBI and their family members. While we acknowledge the primacy of this perspective, health professionals involved with these patients may hold different views. Individuals may have been more likely to participate if they were experiencing difficulties, as the majority of participants had significant persistent disability. It is possible that the young adults had different needs from older adults in this study given the transition to independence that occurs as a child becomes an adult. However, small numbers and the severity of the TBI prevented a closer examination of this group's particular needs. Only people with TBI and family members fluent in English were included in the study. Further studies should explore the experiences people with TBI and family members from non-English speaking backgrounds, as they could face more and/or different challenges to receiving care coordination. Additionally, future studies could focus on the experiences of people who did have an active care coordinator to examine how their experiences differed to people without a care coordinator.

Conclusion

Four years after injury many people with severe TBI experienced persistent issues and changing needs, and were engaged with multiple services that required regular interaction with complex health, disability, and insurance systems. Our results suggest that when no key person coordinated long-term care, and/or issues existed with care coordination activities, people with TBI and their family members perceived restricted options for service access, continuity, quality and collaboration. Given the complex and long-term nature of TBI recovery, more effective coordinated care that leverages, links and integrates knowledge and services, could reduce individual, family and societal burden, and support optimal care and recovery outcomes.

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Declaration of interest

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Reference

- [1] US National Institute of Health Consensus Development Panel on Rehabilitation of Persons With Traumatic Brain Injury. Rehabilitation of persons with traumatic brain injury. *JAMA* 1999;282:974-83.
- [2] Moore M, Kiatchai T, Ayyagari RC, Vavilala MS. Targeted areas for improving health literacy after traumatic brain injury. *Brain Injury* 2017;31:1876-81.
- [3] Kroll T, Neri MT. Experiences with care co-ordination among people with cerebral palsy, multiple sclerosis, or spinal cord injury. *Disability and Rehabilitation* 2003;25:1106-14.
- [4] Leith KH, Phillips L, Sample PL. Exploring the service needs and experiences of persons with tbi and their families: The south carolina experience. *Brain Injury* 2004;18:1191-208.
- [5] Solovieva TI, Walls RT. Barriers to traumatic brain injury services and supports in rural setting. *Journal of Rehabilitation* 2014;80:10-18.
- [6] Jaffee MS, Helmick KM, Girard PD, Meyer KS, Dinegar K, George K. Acute clinical care and care coordination for traumatic brain injury within department of defense. *Journal of Rehabilitation Research & Development* 2009;46:655-65.
- [7] Pressman HT. Traumatic brain injury rehabilitation: Case management and insurance-related issues. *Physical Medicine and Rehabilitation Clinics of North America* 2007;18:165-74.
- [8] McColl MA, Shortt S, Godwin M, Smith K, Rowe K, O'Brien P, Donnelly C. Models for integrating rehabilitation and primary care: A scoping study. *Archives of Physical Medicine and Rehabilitation* 2009;90:1523-31.
- [9] Boon H, Verhoef M, O'Hara D, Findlay B. From parallel practice to integrative health care: A conceptual framework. *BMC Health Services Research* 4(1):15. <http://dx.doi.org/10.1186/1472-6963-4-15>. [Accessed 2017 July 01].
- [10] Schultz EM, Pineda N, Lonhart J, Davies SM, McDonald KM. A systematic review of the care coordination measurement landscape. *BMC Health Services Research* 13(119). <http://go.galegroup.com.ezproxy.lib.monash.edu.au/ps/i.do?p=AONE&sw=w&u=monash&v=2.1&it=r&id=GALE%7CA330186982&asid=23baf094068c54b52addf5bc19d994c5>. [Accessed 2017 July 28].
- [11] Davies GP, Williams A, Larsen K, Perkins D, Roland M, Harris M. 2008. Coordinating primary health care: An analysis of the outcomes of a systematic review. *Medical Journal of Australia*. p. S65-S68.
- [12] Walsh J, Harrison JD, Young JM, Butow PN, Solomon MJ, Masya L. What are the current barriers to effective cancer care coordination? A qualitative study. *BMC Health Services Research* 2010;10:132.
- [13] Carayon P, Alyousef B, Hoonakker P, Hundt AS, Cartmill R, Tomcavage J, Hassol A, Chaundy K, Larson S, Younkin J et al. Challenges to care coordination posed by the use of multiple health it applications. *Work* 2012;41 Suppl 1:4468.
- [14] Jones C, Vu M, O'Donnell C, Anderson M, Patel S, Wald H, Coleman E, DeWalt D. A failure to communicate: A qualitative exploration of care coordination between hospitalists and primary care providers around patient hospitalizations. *Journal of General Internal Medicine* 2015;30:417-24.
- [15] Bodenheimer T. Coordinating care — a perilous journey through the health care system. *New England Journal of Medicine* 2008;358:1064-71.
- [16] Wagner E, Austin B, Davis C, Hindmarsh M. Improving chronic illness care: Translating evidence into action. *Health Affairs* 2001;20:64-78.

- [17] Maeng DD, Martsof GR, Scanlon DP, Christianson JB. Care coordination for the chronically ill: Understanding the patient's perspective. *Health Services Research* 2012;47:1960-79.
- [18] Australian Department of Health and Ageing. 2007. The national evaluation of the second round of coordinated care trials: Coordination of care and efficiency of healthcare: Lessons from the second round of Australian coordinated care trials: Final report. In: Australian Department of Health and Ageing, editor. Canberra: Commonwealth of Australia.
- [19] Ta'eed G, Skilbeck C, Slatyer M. Service utilisation in a public post-acute rehabilitation unit following traumatic brain injury. *Neuropsychological Rehabilitation* 2015;25:841-63.
- [20] Turner BJ, Fleming J, Ownsworth T, Cornwell P. Perceived service and support needs during transition from hospital to home following acquired brain injury. *Disability and Rehabilitation* 2011;33:818-29.
- [21] Heinemann AW, Sokol K, Garvin L, Bode RK. Measuring unmet needs and services among persons with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation* 2002;83:1052-59.
- [22] Pickelsimer EEDA, Selassie AWD, Sample PLP, W. Heinemann AP, Gu JKM, Veldheer LCP. Unmet service needs of persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation* January/February 2007;22:1-13.
- [23] Munce SEP, Laan RV, Levy C, Parsons D, Jaglal SB. Systems analysis of community and health services for acquired brain injury in Ontario, Canada. *Brain Injury* 2014;28:1042-51.
- [24] Ownsworth T, Turpin M, Carlson G, Brennan J-A. Perceptions of long-term community-based support following severe acquired brain injury. *Brain Impairment* 2004;5:53-66.
- [25] Hodgkinson A, Veerabangsa A, Drane D, McCluskey A. Service utilization following traumatic brain injury. *Journal of Head Trauma Rehabilitation* 2000;15:1208-26.
- [26] Prang K-H, Ruseckaite R, Collie A. Healthcare and disability service utilization in the 5-year period following transport-related traumatic brain injury. *Brain Injury* 2012;26:1611-20.
- [27] McCluskey A, Johnson M, Tate R. The process of care management following brain injury: A grounded theory study. *Brain Impairment* 2007;8:293-311.
- [28] Cameron P, Gabbe B, McNeil J, Finch C, Smith K, Cooper J, Judson R, Kossmann T, Cooper D. The trauma registry as a statewide quality improvement tool. *The Journal of Trauma* 2005;59:1469-76.
- [29] Gabbe BJ, Braaf S, Fitzgerald M, Judson R, Harrison JE, Lyons RA, Ponsford J, Collie A, Ameratunga S, Attwood D et al. Restore: Recovery after serious trauma—outcomes, resource use and patient experiences study protocol. *Injury Prevention* 2015;21:348-54.
- [30] Pope C, Mays N. 2006. *Qualitative research in health care*. Oxford: Balckwell Publishing.
- [31] Liamputtong P. 2009. *Qualitative research methods*. Sydney: Oxford University Press.
- [32] Association for the Advancement of Automotive Medicine. 2008. The abbreviated injury scale 2005, update 2008. Des Plaines, Illinois: AAAM.
- [33] Teasdale G, Jennett B. Assessment of coma and impaired consciousness: A practical scale. *The Lancet* 1974;304:81-84.
- [34] What we can pay for. 2018. Victoria, Australia: Transport Accident Commission; [accessed 4th May]. <http://www.tac.vic.gov.au/clients/what-we-can-pay-for>.

- [35] Work and income. 2018. Victoria, Australia Transport Accident Commission; [accessed 4th May]. <https://www.tac.vic.gov.au/clients/work-and-income>.
- [36] Transport Accident Commission. 2017. Preparing to go home: Major injuries. In: Transport Accident Commission, editor. Victoria: Victoria State Government.
- [37] Productivity Commission. 2011. Disability care and support. Canberra.
- [38] Tongco MDC. Purposive sampling as a tool for informant selection. *Ethnobotany Research and Applications* 2007;5:147-58.
- [39] Ritchie J, Spencer L. 1994. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, editors. *Analyzing qualitative data*. London: Routledge. p. 173-94.
- [40] Creswell JW. 2007. *Qualitative inquiry & research design : Choosing among five approaches*. Thousand Oaks: Thousand Oaks : Sage Publications.
- [41] Holcomb EM, Millis SR, Hanks RA. Comorbid disease in persons with traumatic brain injury: Descriptive findings using the modified cumulative illness rating scale. *Archives of Physical Medicine and Rehabilitation* 2012;93:1338-42.
- [42] Winter L, Moriarty HJ. Quality of relationship between veterans with traumatic brain injury and their family members. *Brain Injury* 2017;31:493-501.
- [43] Chan J, Parmenter T, Stancliffe R. The impact of traumatic brain injury on the mental health outcomes of individuals and their family carers 8(2):155-64. <http://search.informit.com.au.ezproxy.lib.monash.edu.au/documentSummary;dn=265986646324825;res=IELHEA>. [Accessed 18th December 2014].
- [44] Tam S, McKay A, Sloan S, Ponsford J. The experience of challenging behaviours following severe tbi: A family perspective. *Brain Injury*.
- [45] Ponsford J, SchÖNberger M. Family functioning and emotional state two and five years after traumatic brain injury. *Journal of the International Neuropsychological Society* 2010;16:306-17.
- [46] Jowsey T, Dennis S, Yen L, Mofizul Islam M, Parkinson A, Dawda P. Time to manage: Patient strategies for coping with an absence of care coordination and continuity. *Sociology of Health & Illness* 2016;38:854-73.
- [47] Australian Commission on Safety and Quality in Health Care (ACSQHC). 2014. *Health literacy: Taking action to improve safety and quality*. Sydney: ACSQHC.
- [48] Nutbeam D. The evolving concept of health literacy. *Social Science & Medicine* 2008;67:2072-78.
- [49] Goodridge D, Rogers M, Klassen L, Jeffery B, Knox K, Rohatinsky N, Linassi G. Access to health and support services: Perspectives of people living with a long-term traumatic spinal cord injury in rural and urban areas. *Disability and Rehabilitation: An International, Multidisciplinary Journal* 2015;37:1401-10.
- [50] Wobma R, Nijland R, Ket J, Kwakkel G. 2016. Evidence for peer support in rehabilitation for individuals with acquired brain injury: A systematic review. *Journal of Rehabilitation Medicine*. p. 837-40.
- [51] Jennekens N, de Casterle BD, Dobbels F. A systematic review of care needs of people with traumatic brain injury (tbi) on a cognitive, emotional and behavioural level. *Journal of Clinical Nursing* 2010;19:1198-206.
- [52] McColl MA, Aiken A, Schaub M. Do people with disabilities have difficulty finding a family physician? *International Journal of Environmental Research and Public Health* 2015;12:4638-51.
- [53] Jackson G, Powers B, Chatterjee R, Bettger J, Kemper A, Hasselblad V, Dolor R, Irvine R, Heidenfelder B, Kendrick A et al. The patient-centered medical home: A systematic review. *Annals of Internal Medicine* 2013;158:169.

- [54] Murgatroyd D, Lockwood K, Garth B, Cameron ID. The perceptions and experiences of people injured in motor vehicle crashes in a compensation scheme setting: A qualitative study. *BMC Public Health* 2015;15:1-10.
- [55] Commonwealth of Australia. 2013. National disability insurance scheme act 2013. Canberra, Australia: Commonwealth of Australia.

Figure 1: Thematic map of what participants perceived as effective and ineffective care coordination

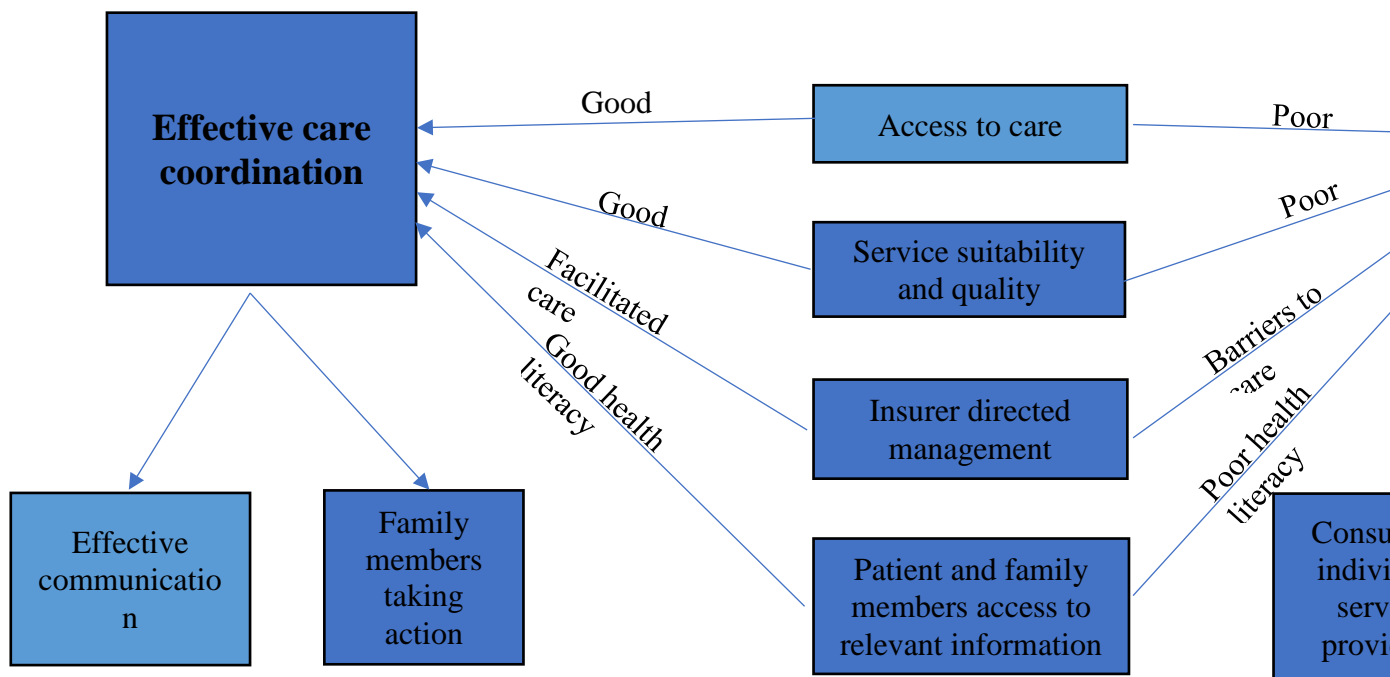


Table 1 Profile of people with severe TBI (n=18)

Descriptor		N
Age	Mean (SD)	35.9 (16.7)
Gender	Male	11
	Female	7
Education	University	4
	Completed high school	3
	Advanced diploma or certificate	4
	Did not complete high school	7
Pre-injury disability	No	12
	Yes ^a	6
Charlson Comorbidity Index (CCI) weight ^b	None	6
	1 or greater	12
Fund Source	Compensable	12
	Non-compensable	6
Mechanism of injury	Transport-related	14
	Non-transport-related	4
Intent	Unintentional events	15
	Intentional events	3
Injury severity score (ISS)	Median (interquartile range)	30 (21-41)
Maximum Abbreviated Injury Scale score for the head region	3	5
	4	9
	5	4
Glasgow Coma Scale (GCS) score	3-5	9
	6-8	9
Major city ^c	No	6
	Yes	11
Index of Relative Socio-economic Advantage and Disadvantage ^d	1-2 (most disadvantaged)	4
	3-4	7
	5 (most advantaged)	6
48 month outcomes		
Glasgow Outcome Scale Extended (GOS-E) ^e	Good recovery	3
	Upper moderate disability	5
	Lower moderate disability	3
	Upper severe disability	4
	Lower severe disability	3
Return to Work ^f	No	6
	Yes	6

^aCollapsed from a scale of mild, moderate, marked and severe.

^bCCI is a weighted index that considers the number and seriousness of comorbid diseases. A weight of 'none' indicates no comorbid conditions, a weight of one or greater indicates the present of comorbid conditions.

Missing data: ^cn=1; ^dn=1

^eCollapsed from 8 categories

^fOf those working prior to injury