Title: Informal Care Management after Traumatic Brain Injury: Perspectives on Informal Carer Workload and Capacity

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Implications for Rehabilitation

- Rehabilitation services need to focus on broad family contexts rather than focus on the injured individual in isolation.
- Understanding the nature of the work being undertaken by informal carers, and their capacity to carry out that work is important when considering supports.
- Rehabilitation professionals need to consider and respond to the impact that changing circumstances have on the capacity of informal care networks to manage care workload.

Informal Care Management after Traumatic Brain Injury: Perspectives on Informal Carer Workload and Capacity

Abstract

Purpose: Much of the support required to live in the community post traumatic brain injury is provided by informal carers. Understanding the nature of caregiving work is important to better support informal carers. This study explored the work being performed by informal carers, and factors impacting on their capacity to manage the workload.

Method: Participants comprised 21 dyads each consisting of an adult with moderate to severe traumatic brain injury and a nominated carer. Thematic analysis was done on semi-structured interviews with injured participants and carers during the 12-month period post-discharge from hospital.

Results: Results revealed 2 main themes and 8 sub-categories: 1) The nature of informal care: describing informal care management work, (personal assistant work; care provider work; family support work; and emotional self-regulation work), and 2) Mediating factors that impacted people's capacity to manage workload (carer intrinsic factors; injured person characteristics; family circumstances; and changes over time.)

Conclusions: Rehabilitation providers supporting people following traumatic brain injury need to focus on broad family contexts; understand the nature of work being undertaken, and carer capacity to carry out that work; and be aware of the unique and changing circumstances of families to better support informal carers.

Keywords: Informal care; traumatic brain injury; caregiving; burden of treatment; qualitative study

Introduction

Traumatic brain injury (TBI) changes lives instantly and permanently, typically resulting in the need for life-long support with a range of life tasks. The support of family and friends is crucial, with strong informal support linked to positive outcomes for people with TBI [1-3]. Following injury, the aim of rehabilitation is to support injured people to adapt and adjust to living in the community. However, much of the required support in areas such as housing, rehabilitation and home care, financial support, and social re-integration is provided by informal carers [4-6]. As substitutes for formal care, these informal networks substantially reduce the cost of care to health services and governments [7].

In 2015, there were 2.7 million unpaid carers in Australia, predominantly female [8], who provided care to the estimated replacement value of AUD \$60.3 billion [9]. The cost-benefits of informal care for society notwithstanding, this shift in responsibility to informal carers can become problematic in terms of burden on caregivers. These unpaid informal carers, although generally willing to support vulnerable family members, may experience a range of psychosocial challenges associated with the workload of providing supportive care, not the least of which arises from mutual obligations within the care context [10, 11]. This burden reduces both the quantity and quality of care that can be provided.

Responding to brain injury is challenging, and the expertise and engagement of support networks varies. Studies have continually shown that primary carers of people with TBI, typically family members, commonly experience increased stress, anxiety and depression; social isolation; and employment disruption, which can result in financial hardship and contribute to greater isolation and difficulty [12-14]. Levine [12] noted the health systems' reliance on informal carers, and underscored the importance of supporting carers stating, “exhausted caregivers may become care recipients, leading to a further, often preventable, drain in resources” (p.1559). Thus, additional burden for caregivers is a

corollary to the reduction in societal cost-related burden that is achieved by shifting care responsibility from formal to informal care networks. The long-term health and wellbeing outcomes for people who require ongoing care and support are dependent on the collective capacity and efficacy of the network to navigate and negotiate complex health and social care systems and post-injury trajectories [15].

The work associated with living with TBI in the community is multi-faceted and potentially burdensome (i.e., workload) [16, 17]. Several factors impact this workload, including the complexity of TBI, which is unique to each person [18]. Additionally, the nature and extent of relational networks, which may be negatively impacted by the injury, also affects workload [19]. Finally, the capacity of relational networks to perform work that is required for individuals to live optimally after injury may also play a role [20]. The balance between workload and capacity is pivotal to understanding the burden experienced by informal carers supporting people with TBI living in the community post-injury. However, despite the significance of the carer role and the volume of carer burden and psychological impact research, little is known about workload and carer capacity in this context. This information is needed to determine how to better support carers and families following TBI. Therefore, this study sought to answer the following research questions 1) what is the nature of the work being performed by informal carers of people with TBI, and 2) what are the factors that impact carer capacity to carry out that work? The perspectives of carers and people with TBI were included.

Method

Qualitative methods are particularly relevant to better understanding the complexities associated with a disability such as TBI [21]. This study utilizes a qualitative study design, including in-depth interviews with injured person and carer dyads at four time points, and the

deductive techniques of thematic analysis. The processes that were used will be explained in additional detail next.

Sample and recruitment

The sample comprised a consecutive series of adults who had recently been discharged from the Brain Injury Rehabilitation Unit of a large metropolitan hospital. Participants were adults who had sustained moderate to severe TBI as determined by the Glasgow Coma Scale (GCS); who were medically stable and able to communicate; had returned to the community rather than a residential institution; and were willing to nominate a carer who was also willing to participate. Using hospital records, 142 individuals were identified who met the inclusion criteria. Potential participants were first contacted at discharge from hospital, and 21 people who had sustained TBI agreed to participate. Of those 21 participants, fourteen were male and seven female. A carer nominated by each participant was also recruited for the study. The majority of carers were female (F=20, M=1), and predominantly the mother of the injured person (12). Eight carers were the spouse of the injured person; and one an ex-partner. (See Table 1 for more details about participants).

[Table 1 about here]

Data collection

Data were collected from dyads comprising the injured person (I) and an informal carer (C) at four time points during a 12-month period post discharge from hospital (see Table 2). In-depth interviews, either by telephone or in person, were used to investigate the post-discharge experiences of both injured and carer participants. All interviews were carried out at a mutually agreed time by a research assistant who had no prior relationship with participants. The same interview protocol was used at each time interval (see Table 3).

Observations were kept as research notes, and relayed back to the research team at regular meetings. Interviews lasted from half an hour to 1 hour.

[Table 2 about here]

Data analysis

Interviews were recorded and transcribed verbatim. Data analysis was an ongoing process, utilising a thematic analysis approach [22]. Prior to conducting data analysis researchers were sensitised to the concept of treatment burden that arises from an imbalance between the work that people are required to do and their capacity to do the work [18;20]. One researcher (MM) read the interview transcripts multiple times to become familiar with the data and note early observations, and generate initial codes. Following initial coding, codes were categorised and themed through an iterative process using NVivo 10 software (QSR 2002). Coded nodes were analysed and summarised by two authors (MM & CE). Tables were used to track frequency of codes over time, and to distinguish differences between accounts of injured participants and their carer. Data that appeared to belong together were categorised together. Two authors (MM & CE) were responsible for generating theme structures, which were then discussed reflexively with the broader team. Throughout the data analysis process, two authors (MM & CE) met regularly to reflect on, and discuss emergent findings. Themes were generated by asking the question “What is this an example of”, until all data could be accounted for, and the most parsimonious theme structure was agreed by the research team.

Ethics

The study protocol was approved by research ethics committees of both the university and the health service. The rules of free and informed consent and of confidentiality of data were respected.

[Table 3 about here]

Results

The results showed that a broad range of informal care activities were carried out by primary carers, with varying levels of support from a broader network of family, friends, social groups, and work colleagues. Based on these results two main themes were identified relating to (1) the nature of the work associated with informal care management, and (2) the mediating factors that impacted people's capacity to manage care.

The nature of informal care: describing informal care management work

Four distinct types of work associated with caring for a person with TBI were identified. These were personal assistant work (i.e., administrative and organising work); care provider work (i.e., learning about injury, engaging in treatment routines, vocational re-integration); family support work (i.e., advocacy, building self-esteem, providing emotional support); and emotional self-regulation work (i.e., managing own responses to grief, loss, change and uncertainty). Each of these roles involved distinct tasks and activities, and were supported or impeded in different ways.

Personal assistant work: practical support

Carers took on a range of administrative and organisational tasks which the injured person was no longer able to manage themselves, functioning much like a personal assistant. These included injury related tasks such as managing legal and financial paperwork; appointment co-ordination; providing transport; and every-day planning, organisational and financial management activities. The responses of both injured and carer participants indicated that responsibility for paperwork was often handed to carers, as one injured participant explained, "*I wouldn't even know what a bill (statement of account) looks like, my wife does it all*" (I015). This responsibility could be burdensome, which was exemplified by one carer participant's response to more paperwork, "*....do you know I didn't even read it, I*

just thought I don't want to know. (I thought) it's another one, I don't want to know" (C018).

A number of participants reported that they were involved in legal processes, either through compensation, insurance, or in one instance in criminal proceedings. Carer participants reported a high level of work associated with these responsibilities, as well as increased stress. Most injured participants were awaiting assessment before getting their drivers licence back, and were therefore dependent on family and friends for transport to appointments, work, or social activities. In the main the personal assistant workload involved skills which were familiar to carers. However, prior to the injury these tasks would have been performed by the injured person. Taken together these activities were time consuming and could add pressure and stress to families lives.

Care provider work: engaging with rehabilitation and recovery

Carer participants typically showed a high level of engagement in ongoing rehabilitation and recovery support, acting as an informal case manager. Multiple tasks were associated with this role including collaboration with services, overseeing rehabilitation activities, supporting social and vocational re-integration, advocacy, and self-education. Most carer participants were actively involved in the injured participant's rehabilitation activities, and acted as a liaison between the injured person and services. Carer participants collaborated with services, monitoring progress and informing health care providers of the person's progress, capabilities and needs. In this regard, treatment continued beyond the service setting, with carers ensuring that care regimes were adhered to. Subsequently, many had developed strategies to incorporate rehabilitation tasks into the everyday lives of the injured person:

One of the new exercises she has to do is to crawl a bit on her arms to get a bit more pressure on it and strength. So we crawl around the floor with (Granddaughter)

which is good. So we make a game out of it which is good. You've got to make it all a bit more interesting instead of just "do this, do that." (C012)

In many cases carer participants played a crucial role in motivating injured participants in areas they sometimes resisted, such as exercising, or socialising. One carer participant noted that she “makes” her injured partner go to the gym, about which he commented, “*she has a timetable for me. She's only happy when I'm busy - busy working*” (I011). The information and knowledge obtained by informal carers was fed back to services, and constituted an important aspect of treatment planning.

Social and vocational re-integration was another important area of rehabilitation, which was typically driven by informal carers. Carer participants described that they were often involved with initiating, organising and overseeing work and/or work experience activities. This transition to employment was typically challenging, with many unknowns about the nature and duration of work the injured person would be capable of undertaking. Carer participants played an important role in monitoring the impacts of employment on the injured person, and adjusting where necessary, as this carer described:

But I think , - and I said to (him) when I saw the roster, I think it's too fast for him to be going from a three day week, three hours a day three day week, to an eight hour day, five day week. (C007)

Carer participants also supported social integration by using a structured approach to maintain access to informal networks. A number of carers reported engaging in activities explicitly aimed at enhancing social interaction, such as described by this carer participant:

This is our plan, we intend to go to church so he (injured son) can meet young people, but not too full on. You know what I mean? So he can meet people that are his age, and that's probably the best way. So that's one of our plans. (C013)

Others focussed on activities which enhanced independence, such as gaining confidence in public places and using public transport. One carer participant worked towards enhancing her daughter's independence after she lost speech through her injury:

...so I said to (injured daughter) "put your talker (assistive device) on the counter and you ask for what you need and make them"- because it's her local shop. (C014)

In the main, care provider work involved knowledge and activities which were unfamiliar to carer participants. They described a process of self-education, where they undertook to learn about the injured person's condition and needs:

Oh yeah, something we didn't expect to happen, happened and I've got to learn more about it to cope with it, and try to understand what happened and how to deal with it.

(C012)

Many carer participants appeared to take responsibility for informing themselves about their injured loved one's condition, *"as the main carer you have to - you just have to [learn about the condition]. I went out of my way to get books and information"* (C013). This process could be hard work, *"It has been a really hard haul - trying to understand it as well. Because it's new for me as well"* (C012). Carer participants frequently described the work of advocating on behalf of the injured person with health professionals, employers, and extended family networks. In these situations, the theme of "fighting" on behalf of the injured person often mentioned. Many carer participants described themselves as experts in relation to their loved ones' needs and capabilities. Statements about carers knowing what was best for their injured family member were common.

Family support: emotional anchoring work

The family support role involved activities and support aimed at assisting the injured person with emotional recovery post injury. Overlap with the care provider role was seen in relation to building confidence and independence through social and vocational re-

integration. However, the family support role refers to the emotional support aspect of those activities, and appeared more familiar to carers. Providing emotional support, encouragement, and activities designed to increase self-esteem, and confidence contributed to emotional recovery. Results showed the importance of this type of support for the wellbeing of the injured person. In many cases, carer participants appeared to take responsibility for the emotional equilibrium of the entire family, not just the injured person. In these families, the carer acted as mediator within the family network; minimising conflict and working to maintain family relationships:

As I try to explain to people - he knows he has this problem (anger outbursts) but it's hard, he can't sort of stop it. That's what I've had to explain to everybody here.

That's where it's been hard. (C006)

This could be a difficult process for carers, and as evidenced in the previous example, at times carer participants appeared to resent the apparent lack of understanding shown by others.

Emotional self-regulation work

Whilst carrying out the work described above, carer participants also described the work of managing their own emotions and concerns. Carer participants expressed grief and loss in relation to changes in the injured person, and loss of the familiarity of life before the injury, as this carer described, *"it's sort of hard because your life changes because of the injury but it's the everyday little things that change"* (C015). This comment conveyed a common experience of how changes in everyday routines, family roles and relationships created an experience of life as suddenly unfamiliar.

Concerns about the injured person's capacity to manage independently were common, *"I just worry about her, not just on one thing. Finances, her health of course, she's still forgetful about certain things...her moods too"* (C005), and the injured person's coping capacity had a

reciprocal impact on carer worry:

It's trying to find that happy medium. If I know he's confident to do something then that's ok, he can do it. But then if I know that he's not confident that's when he still worries me. (C006)

The work of managing emotions associated with loss and change appeared to be complicated by a lack of certainty about the future. Unknowns relating to long-term injury prognosis, pending compensation, employment prospects, and vocational re-integration converged to create significant uncertainty in the lives of both participant groups. For example, this carer described how unknowns associated with return to work created additional worry:

He's really keen on getting back to work. He was a workaholic prior to the accident anyway. But at the same time, it worries me how he's going to cope when he does go back to work. (C001)

For many participants, uncertainty meant that life at this time was described as being “on hold” or “in limbo.” Living with uncertainty became another source of work, which carer participants managed with varying degrees of ease or distress.

Mediating factors that impacted people's capacity to manage workload

A range of factors served to increase or diminish the workload experienced by carer participants. These included factors intrinsic to individual carers (e.g., attitudes and beliefs about injury and carer role; coping skills); injured person characteristics (e.g., attitudes and beliefs about injury; independence and self-management capacity; relationship with carer); family circumstances (e.g. life-stage of family; available supports); and changes over time (e.g. changes associated with injury recovery, changed family circumstances, support changes). The interaction of these factors impacted on the capacity of carer participants to successfully provide ongoing care and support.

Mediating factors intrinsic to carers

Carer participants' attitudes to the injury and to the carer role, and their intrinsic capacity to cope with emotional work impacted their experience of caring. Carer participants expressed a range of different attitudes towards their role, which affected how they engaged with caring work, and the perception of burden. For some, although the challenges were acknowledged, accepting the carer role was not questioned:

I am the main, well I'm the only caregiver. There's no one else, but it's not a hard thing or anything like that because I love (spouse), so there's no problem there.
(C015)

Even though we've sort of put ourselves on hold with a lot of things, we don't mind. (Spouse) and I would do anything to help him (injured son) in any way we can.
(C006)

Other carer participants appeared to more actively resist caring responsibilities and impacts:

Because it's just, because it's a long-term thing, it just seemed as if it had been forever, and to a degree you want your own life back. I don't mean that in a nasty way. But you know, everything (in your own life) goes on hold. (C021)

There were also differences in carer participants' attitudes towards the injury. Some were positive, and expressed hope for the future:

I'm just lucky that it's turned out as well as it has. When I've read about all those others that haven't, and we both sort of thank our lucky stars that well, we're still able to get on with living. (C002)

Many carer participants talked about a need to "get back to normal", and often expressed frustration with the slow process of recovery. "We seem to have stopped. We don't seem to be moving anywhere now" (C021). Carers who were less concerned about progress did not express the same worry about recovery:

I definitely believe there will be more improvements. More improvements in his confidence and things like that, but I think it will be a bit more long-term than just a couple of months. (C017)

Carer coping strategies appeared to enhance their capacity to manage. Carer participants mentioned a variety of coping strategies, which included focussing on achievements and gains, taking time away from caring, getting on with life, and finding positives and things to be grateful for. Some carer participants reflected on their own process of coping, noting the importance of “*knowing the triggers*” (C014) in relation to their own coping, and organising respite when needed.

Injured person characteristics

Carer capacity notwithstanding, injury characteristics also affected the workload experienced by carer participants. Challenging behaviours in the injured person created relationship conflict, and added significant pressure to carers. One carer participant displayed increasing levels of stress about her partner’s personality changes, reportedly locking her injured partner out of the house as her only avenue for respite, “*Yeah! Just so I don’t have to listen to what he’s saying sometimes. It’s the same thing all the time and it just drives you up the wall*” (C011).

In cases where injured participants were less motivated and less independent, a greater emotional workload was evident for carer participants, who worried about their loved one’s recovery and wellbeing. Conversely, where the injured person was more independent and self-sufficient there was less work and less worry for carer participants:

I don’t think I’ve got as many concerns as I did have. He is doing really well. He’s fallen on his feet and got a full time job he enjoys...I’m not actually worried about anything at the moment. (C001)

Injured participants expressed a range of attitudes towards their injury from predominately accepting and positive, or predominantly angry and depressed. When injured participants were positive, independent and coping well, carer participants were more positive:

Oh, I've got nothing to complain about. (She) is an inspiration to me. The fact that she can do so much for herself, and she doesn't complain. She never complains about it. She gets frustrated at times. But she copes really well. (C014)

In cases where the injured person appeared to struggle to accept the injury, this was mirrored in the emotional workload for carer participants.

Family circumstances

Other factors that mediated capacity to manage workload included family circumstances such as the life stage of the family, and the availability and appropriateness of formal and informal support. Families with young children reported additional challenge. In some cases, carer participants lived away from the injured participant, and these carers did not report the same level of difficulty as those living with injured participants, indicating the value of respite.

The efficiency and effectiveness of formal support, combined with the availability of informal support, had a significant impact on participants' experiences. Although participants reported positive experiences with formal support services, many also reported dissatisfaction with the help they received. Long wait-times for tests and assessments were described as frustrating, and could be a barrier to vocational re-integration and independence. Some participants described situations where formal advice was perceived as inappropriate in their particular circumstances.

Participants reported a range of activities undertaken by extended informal support networks made up of immediate and extended family members, close friends, and acquaintances. These networks improved outcomes for the injured person and reduced the

workload for primary carers. Results varied in relation to the extent of, and reliance on this support. Many injured participants commented on the importance of extended family and friends for support:

I'm probably pretty spoiled because I have a pretty large support group...of my mate around the corner and couple of my wife's girlfriends. That sort of thing. So it's only a matter of saying, "hey I'm stuck", and three or four people put their hand up and say "we'll come and help you." (I007)

If friends were involved, they typically provided social support and encouragement. These interactions were important for the wellbeing and self-esteem of injured participants, as well as providing respite for carer participants. In some cases, friend support extended to work opportunities. One injured participant described the important role his friendships played in his recovery:

That's what I said to my friends too, I wouldn't be where I am if they sort of didn't stick by me and make me think that there was something to get out for kind of thing. But not just lying there thinking "I don't have any friends outside any more". What's the point? (I006)

Conversely, some injured participants reported little support beyond the primary carer. Although the lack of a network had negative impacts for some, for others it was a deliberate choice. Two families described extended support networks in negative terms:

...family and friends try to help and actually do damage... I just let them know. Just tell them how I feel and that's about it. Just for them to back off and leave me to be. Leave me to my own devices. (I009)

As well as helping the injured person, support networks also played an important role in emotional support for carer participants and providing assistance to the family as a whole.

For example, one participant described a network of family and friends providing added support and guidance for his children after his brain injury:

I've got a little group of people here around me - a group of friends who have always been there. Fortunately, they've always been on the right track most of my friends. So they've been able to steer, well not so much steer the kids, but just explain some things the kids don't understand when (spouse) is not around. It's worked out pretty well. (I007).

Changes over time

The longitudinal focus of the study revealed that workload was not static, and participants needed to adjust to changing circumstances.

For some carer participants, workload diminished over the course of the study as injured participants recovered, became more independent, and in some cases returned to work. However, emotional workload increased for many carers. Early hopes could be replaced by frustration for both carer and injured participants when recovery appeared to slow down or plateau:

I think it's plateaued in my physical problems, and just with the head and everything, which is a bit frustrating and depressing. But I guess I've just got to accept the fact that I might not- I might get better...this is a complete and utter change of orchestrated life for me, and I find that hard to deal with. (I008).

In cases like this, where injured participants became increasingly disheartened, emotional workload for carer participants increased. Similarly, if return to work was difficult for injured participants, then carer workload increased.

The results showed that fluctuating family circumstances impacted on carer workload and capacity. Over the course of the study, many participants experienced changes in life circumstances outside of the injury. Events such as the birth of children, changes in

accommodation, retirement, and illnesses were reported. These changed circumstances impacted people's ability to cope, and formal supports often failed to address these emerging needs. For one family, the birth of twins created enormous stress for the carer participant who needed to balance the demands of babies with those of her injured partner:

I don't, I don't know if it's the way he is or if he just doesn't try because he isn't interested in it. But if I'm getting ready to go somewhere and I'm a bit late or a bit behind – and you've still got to do- like pack your bag and get their nappies changed and do something else. And it's just like if he did that while I did this, it would be good. But you've got to give exact instructions for something to happen. And when you're trying to think of something that you're doing, you can't (give exact instructions). (C011)

Likewise, changing family circumstances impacted the level of support that families needed, as one injured participant with teenage children explained:

Also my kids, their teenage years and I love them dearly. You just need a back-up. And I am ringing their father (informal carer) more often, but it's just, yeah, every issue is trying (I005).

In another example an injured participant explained her fears in relation to the imminent birth of her baby:

I think that everything boils down to whether I'm going to be able to handle it (giving birth) when it happens - when I have it. Like it's all new to me. There's a first time for everything. And like I don't know anything. And yeah, so, it's a bit worrying if I can handle it all. (I012)

In these examples participants indicated that support to navigate these changes were lacking.

Many participants reported that access to support also changed over time. The issue of changes in formal support staff was mentioned by a number of participants, and the need to

“start again” with a new case manager meant additional work for carer participants. For most participants, formal supports had stopped by the end of the study, meaning friends and family became the only source of support, as exemplified by this carer:

We don't really get any other help. A friend comes past and takes him (injured person) to the gym whenever he goes. But that's about it really. Just like friends when they pop in to see him or ask if he wants to do something. Apart from that there's nothing else really. (C007)

A number of participants also reported that informal support networks diminished over time, “only us. The others are all - the family are too busy with their own lives really. They were really very good in the early days” (C021).

Discussion

There are three important findings that arise from this study. First, although it is self-evident that TBI disrupts the lives of injured individuals, carers lives are equally disrupted. Second, in the midst of this disruption, carers need to adapt to work that arises because of the injury—work that is unanticipated, variable, and for which carers report varying degrees of capacity to perform. As a result, carers experience differing levels of burden. Third, although formal support provides necessary care for injured people, large gaps in care provision remain unfilled if carers do not have sufficient capacity to respond. In this section we will discuss each of these key findings separately, and then interpret these findings in the context of service provision.

Biographical disruption of families

The concept of *biographical disruption* has been used to describe how the sudden onset of illness impacts on an individual's experience of every-day life and relationships, and the concomitant impact on self- identity [23]. The biographical impact of moderate to severe TBI for injured people is self-evident, particularly in relation to relationship change and

future uncertainty. The results of the current study show that, similar to Bury's [23] description of biographical disruption caused by chronic illness, TBI disrupts the biography of entire families. Familiar rhythms of everyday life are disrupted, wherein the rules of reciprocity and mutuality within relationships are challenged, and expectations and plans of the family unit must be re-examined [23, 24]. The everyday familiarity of established structures and ways of working are displaced, and injured individuals and their families need to navigate a new and different "everyday" [25]. This everyday familiarity can be further disrupted by ongoing shifts in injured persons' sense of self and understanding of their own personal identity [26]. Within this context, families are required to adjust their expectations and hopes for future realities. Results suggest that these new realities are not always welcome by carers, can be inordinately frustrating, and are associated with a need to self-regulate their own emotions in ways not previously required. Thus, although some authors have identified that restoration of personal narrative is essential after TBI [27], it is equally important that carer narrative is similarly restored in a way that best supports the family to adjust to their new "everyday".

The burden of unanticipated and unrecognised work

Following TBI, the disruption caused by changed roles and relationships can mean shifts in the ways carers function, typically involving a switch from a social to a supportive orientation, focused on care needs [28, 29]. It is well recognised that when families need to move from relationships based on familiar patterns of interaction to relationships involving care work, carer burden or burden of care is often associated [30-32]. In this study, carer burden was especially evident when carers performed multiple care roles (e.g., they were primary carers for an injured spouse as well as children; or they needed to take greater responsibility for family emotional wellbeing, as well as personal assistant roles, while simultaneously self-regulating their own emotional responses). These roles and

responsibilities taken on by carers involved work that was unanticipated, and/or unrecognised, and could be burdensome. Results showed that carer perceptions of burden were increased by treatment relevant requirements. For example, carer participants identified that they were often required to transport the injured person to and from appointments. They also took responsibility for becoming informed about the outcomes of the injury and interpreting those outcomes into actions with the goal of optimising chances for improving the health and wellbeing of the injured person. Carer participants indicated that they managed financial, legal and medical relevant information relating to the injury. They also advocated for the individual in multiple arenas. Finally, they often waited for long periods of time for information from healthcare professionals. The additional burden delegated to informal carers by more formal support networks (i.e., health, vocational and social care systems) has been described by May and colleagues as treatment burden [20], and is either largely unidentified or not well acknowledged in the population of people who experience TBI and their families. The hidden or invisible changes that are often experienced by injured people post TBI [24] also play out in the arena of informal support networks. Thus, alongside care burden, carers in this study identified that they were performing significant amounts of treatment related work with little apparent recognition or negotiation. This work was distributed to them by default. For example, once formal support was no longer available, families often became the only support mechanism available to the injured person.

Factors affecting capacity to perform the required work

Results showed that the capacity to take on the workload of informal care was impacted by multiple factors including those intrinsic to carers and the injured person, as well as changeable factors including available support, and family circumstances. Factors intrinsic to carers such as coping strategies and attitudes to the caring role affected their experiences. Participant responses revealed a range of attitudes towards the role of carer. Some carers

willingly accepted, and appeared confident with a caring role. However, others found it difficult to manage. Although some carers described caring work as overwhelming, others appeared to experience much less distress; describing aspects of the caring role as an expression of love, and with a sense of inspiration. These results are reflective of earlier studies which suggest that despite the stress of caring, families “feel good” about their ability to provide necessary care for their loved one [33, 34]. The corollary of this being wherever families feel the caring role is beyond their capacity, increased distress and dysfunction is likely.

Burden is a reflection of the interaction between workload and capacity [18]. In this study, we found that once a new “everyday” was established, the relationship between workload and capacity was not static. Rather, multiple factors within the external environment interacted in complex ways to impact the ability of families to perform the work that needed to be done. When broader informal networks were available (e.g., friends, social groups, larger family groups), workload could be shared, and entire relational networks had greater inherent capacity to perform the required work [20]. There is a large body of literature that supports the importance of broad informal networks, especially in relation to the health and wellbeing benefits of increased social connectedness [4, 35, 36]. Future research needs to explore the nature of work that broad networks surrounding people with TBI are doing, how that work is distributed, and the factors that impact the capacity of these networks to perform the work of families and injured people following TBI.

Conclusion

The results have a number of possible implications for service delivery. First, the unique nature of families was evident, suggesting that services must respond to broad family contexts rather than focus on the injured individual in isolation. Second, the work associated with ongoing support for people with TBI needs to be recognised and negotiated. This need

for acknowledgement is especially important for work that is hidden, or additional work that occurs because of changes in life circumstances or the demands of service systems. Changes can occur long after formal support has been withdrawn, suggesting that families need the opportunity to re-engage with formal support at these times. Finally, policy changes that impact on the work to be performed by informal care networks (e.g., the introduction of the National Disability Insurance Scheme in Australia) necessitate assistance for informal carers who are already providing multiple support roles, to adapt to this new and unfamiliar work. Finding ways of adequately compensating informal carers for the gratuitous care that they already provide will be essential if an increased reliance on unpaid informal care is to be avoided.

Limitations

The authors acknowledge that results may not be generalizable beyond the context in which the study was conducted. Moreover, the work types identified may not be the only work that carers engaged in.

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Table 1
Participant Details

ID	Injured person Gender	Age @ injury	Injury Severity	Accommodation status (Change post injury)	Pre-injury Employment status	Employment Status @ IV4	Carer: Gender/ relationship
001	M	40	Severe	Lives alone-separated from partner post-injury	Truck Driver (Handed in plates as result of injury)	Self-employed	F ex-partner (Lives apart)
002	M	59	Severe	Spouse- unchanged	Real Estate Agent	Unemployed- forced early retirement	F Spouse
003	M	20	Moderate	Spouse, baby-unchanged	Sheet metal worker	Resumed previous employment	F Spouse
004	F	20	Severe	Moved back in with parents	Harness racing	Unemployed	F Mother
005	F	42	Moderate	2 teenage children-unchanged	Office work	Part time office administration (different setting).	F Mother (lives apart)
006	M	19	Severe	Family home; parents, sibling/ sibling partner moved in	Carpenter	Volunteer work	F Mother
007	M	35	Missing Data	Living with spouse and 4 children at home	Pawn broker	Logistics (admin)	F Spouse
008	M	50	Severe	Spouse, teenage children- unchanged	Forklift Driver	Unemployed (awaiting payout).	F Spouse
009	M	31	Severe	Moved back with parents post-injury	Drilling rig	Part time volunteer meals on wheels	F Mother
010	F	22	Moderate	Spouse, baby-unchanged	Graduated Urban planning degree when injured	Working for her Father/ Childcare @ TAFE.	M Spouse
011	M	31	Severe	Spouse, toddler, twins born	Truck Driver/ electrician	Unemployed	F Spouse
012	F	27	Severe	Back with parents post-injury, then sister-parental separation	Fitness centre promotion	Unemployed (Due to give birth)	F Mother (moved during study)
013	M	20	Severe	Parents- unchanged	Labouring	Volunteer gardening	F Mother (separate @ hospital stay)
014	F	20	Severe	Moved back into mother's home; Later with Mother/Step Father	University student	Volunteer	F Mother
015	M	56	Severe	Spouse- unchanged	Plasterer's labourer	Unemployed (unable to work)	F Spouse
016	F	44		Alone-unchanged	Missing Data	Missing Data	F Mother
017	M	29	Severe	Living with spouse, 2 children-unchanged	Panel beater	Panel beater	F Spouse
018	M	17	Severe	Family home with parents and sibling-unchanged	HSC student	Unemployed	F Mother
019	M	20	Severe	Family home with parents and 1	Retail	Unemployed	F Mother

				sibling/ Sibling left due to conflict			
020	M	17	Severe	Parents- unchanged	Secondary School student	Repeating year 12	F Mother
021	F	35	Severe	Moved back with Mother	Not disclosed	Unemployed	F Mother

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Table 2

Interview Schedule

Participant Dyad	Time post injury IV01	Interview 1 F = face to face T = telephone	3-month follow up (IV02)	7-month follow up (IV03)	12-month follow up (IV04)
I001	14 months	T	F	F	F
C001		T	F	F	F
I002	12 months	T	-	-	T
C002		T	-	-	T
I003	15 months	T	-	-	T
C003		T	-	-	T
I004	12 months	T	-	-	-
C004		T	-	-	-
I005	15 months	T	F	F	T
C005		T	T	T	T
I006	12 months	T	T	T	T
C006		T	T	T	T
I007	7 months	T	T	T	T
C007		T	T	T	T
I008	12 months	T	T	F	F
C008		T	T	T	T
I009	18 months	T	T	F	T
C009		T	T	T	T
I010	22 months	T	T	T	T
C010		T	T	T	T
I011	17 months	F	F	F	T
C011		F	F	F	F
I012	14 months	T	T	T	T
C012		T	-	T	-
I013	14 months	F	F	F	F
C013		F	F	F	T
I014	16 months	F	F	F	F
C014		F	F	F	F
I015	12 months	F	T	F	T
C015		F	T	F	T
I016	3 months	T	T	T	T
C016		T	T	T	T
I017	18 months	F	T	-	-
C017		F	-	-	-
I018	9 months	F	F	T	T
C018		F	F	T	T
I019	10 months	T	F	T	T
C019		T	-	T	F
I020	9 months	T	T	T	T
C020		T	T	T	T
I021	16 months	F	F	-	-
C021		F	F	-	-

Table 3

Interview Protocol

Person with TBI

- What concerns you most about your present situation?
 - What do you hope will change over the coming months?
 - Do you think your condition has changed since we last spoke?
 - Who gives you most help at the present time
-

Informal Carer

- What concerns you most about the present situation?
 - What do you hope will change over the coming months?
 - Who, apart from yourself, provides the most help for ... at the present time?
-

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