Linked Lives: The Experiences of Family Caregivers During the Transition from Hospital to Home Following Traumatic Brain Injury

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The transition from hospital to home following traumatic brain injury (TBI) has been identified as the point where responsibility for care shifts from rehabilitation services to informal family caregivers. There has, however, been little research examining the experiences of family members during this important transition that involves adopting or, in some cases, resuming a caring role (e.g., a parent caring for an adult child). The aim of this qualitative investigation was to understand the experiences of family caregivers during the transition from hospital to home, defined as the first six months postdischarge. The sample included 10 family caregivers, of which all were female and either a mother, spouse or ex-partner of an individual with TBI. Semistructured interviews were conducted on average nine months following community reentry and data were analysed thematically using a framework approach. The overarching theme was that caregivers wished to move past the injury. This desire to move forward stemmed from a realisation of how their life had changed and the weight of the care responsibility. Caregivers were also aware of how the life of the individual with a TBI had changed and hoped for a return to normality (by regaining independence, engaging in meaningful occupation and having meaningful relationships). Implications of the findings for research and clinical practice are discussed. There is a need for services to support family caregivers during the transition from hospital to home.

Keywords: transition, family caregiver, community integration, lived experience

Traumatic brain injury (TBI) is considered to be a major life event due to the complex and often persistent nature of the resultant physical, cognitive, emotional and behavioural impairments (O'Connor, Colantonio, & Polatajko, 2005; Tate, Broe, Hodgkinson, Cameron, & Soo, 2003). The majority of individuals with TBI receive care in hospital before being discharged to a home or community environment (Tooth et al., 2001) and this initial period of integration back into the community has been identified as the transition phase (Turner et al., 2007; Turner, Fleming, Ownsworth, & Cornwell, 2008). However, research has identified long-term challenges for individuals with TBI including problems maintaining employment, social networks and independence (Doig, Fleming, & Tooth, 2001). As a result, many individuals with TBI require support to live in the community,

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which is most often provided informally by the individual's family members or friends (Australian Bureau of Statistics, 1993; Penna et al., 2010). As the need for support can persist for several years after discharge from hospital, or in some cases for the remainder of the individual's lifetime, TBI can have a profound impact on the life course of all family members.

Life course theory is a paradigm for examining the patterns of lives and how the life course is shaped by social, cultural and historical influences (Elder & Giele, 2009). A transition is defined as a change in social roles and responsibilities and understanding individuals' experiences during transition is a key aspect of the life course theory (Elder & Giele, 2009). The transition from hospital to home following TBI is a significant transition for family members as it represents the time where the responsibility for providing care shifts from professional staff to the family (Michels, 1988; Turner et al., 2008). It is therefore important to understand the experiences and perceptions of family caregivers during the transition phase to inform improvements to service delivery to meet the needs of family members of people with TBI.

Research has recognised the important but often challenging role of family caregivers of individuals with TBI. Several quantitative studies have demonstrated the presence of subjective burden and emotional distress (i.e., clinically significant levels of anxiety and depression) among family caregivers, including during the transition from hospital to home (Kreutzer, Rapport, et al., 2009; Livingston et al., 2010; Marsh, Kersel, Havill, & Sleigh, 1998; Turner et al., 2010). Additionally, family caregivers can experience social changes that include changes in their roles, relationships, financial situation and social isolation (Fraser, 1999; Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Leathem, Heath, & Woolley, 1996). Factors associated with burden and distress among caregivers include behavioural changes in the individual with TBI, family coping styles, injury severity and time postinjury (Knight, Devereux, & Godfrey, 1998; Kreutzer, Rapport, et al., 2009; Livingston et al., 2010; Wells, Dywan, & Dumas, 2005). Socioeconomic factors such as the availability of supports and financial situation have also been linked to caregiver functioning (Ergh, Rapport, Coleman, & Hanks, 2002).

Quantitative research (primarily using survey methodology) has examined the service and support needs of caregivers of individuals with TBI living in the community, however, this has varied in time frame from two weeks to 14 years postinjury. Access to information, reassurance regarding the quality of the professional care, support for emotional and psychological problems (for both the individual with TBI and the caregiver), as well as guidance on how to care for the individual with TBI and plan for the future, were commonly identified needs (Kreutzer, Serio, & Bergquist, 1994; Murray, Maslany, & Jeffery, 2006; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007). Caregivers reported great dissatisfaction with access to services postdischarge from hospital and typically felt ill-prepared and unsupported in the caring role (O'Callaghan, McAllister, & Wilson, 2011; Rotondi et al., 2007). As quantitative research consistently highlights the negative consequences of adopting a caring role following TBI (Livingston et al., 2010; Turner et al., 2010) and the varied and often unmet support needs of caregivers (Kreutzer et al., 1994; Murray et al., 2006; Rotondi et al., 2007), further qualitative research is required to better understand the experiences of family caregivers living with an individual with TBI and the factors influencing caregiver burden.

A small number of qualitative studies have been conducted examining the experiences and perceptions of family members on living with and supporting an individual with acquired brain injury (ABI). Some of the key themes that have been described include grieving or adjusting to changes in the individual with ABI, feeling alone in the caregiver role, feelings of uncertainty regarding the wellbeing and future of the individual with TBI, and aspects of caregiver burden — including having to be constantly available and experiencing physical or emotional health problems (Backstrom & Sundin, 2007; Johnson, 1995; Jumisko, Lexell, & Soderberg, 2007). Jumisko et al. (2007) identified that caregivers were very willing to step into this caring role and placed their own needs behind those of the individual with TBI who was perceived to have greater life challenges.

Hope was described in relation to family member experiences following brain injury. During the period of inpatient rehabilitation, caregivers in one study hoped that their relative with ABI would return to their former activities, in particular work or study (Gebhardt, McGehee, Grindel, & Testani-Dufour, 2011). However, in a study examining essay data provided by spouses of an individual with TBI between 1 and 30 years postinjury, spouses described feeling both helpless and hopeless (Chwalisz & Stark-Wroblewski, 1996). The apparent incongruity between family hopes for the future during inpatient rehabilitation, and the subsequent experiences of burden and hopelessness linked to caring for an individual with TBI in the community, reinforces a need for further qualitative research into caregiver experiences during the transition from hospital to home.

Qualitative research has also described positive aspects of family member experiences following brain injury. Some caregivers described having a greater appreciation for life and a deeper relationship with both the individual with ABI and other people in their life (Backstrom & Sundin, 2007; Jumisko et al., 2007), as well as a sense of pride in how they had coped with life changes following the injury (Jumisko et al., 2007). Caregivers have also described having an inner strength, which was important in maintaining hope for recovery and managing the added responsibilities associated with caregiving (Gebhardt et al., 2011). Observing improvements in the individual with ABI, engaging in valued activities outside of the home and being able to talk to others about their experiences were sources of strength for family caregivers (Backstrom & Sundin, 2007; Jumisko et al., 2007).

Qualitative research has highlighted the varied and complex nature of caring for a relative with ABI. The current research, however, has focused on exploring caregiver experiences during inpatient rehabilitation (Gebhardt et al., 2011), in the first month poststroke (Backstrom & Sundin, 2007), or after many years living in the community (Jumisko et al., 2007). There has been limited qualitative research that explicitly examines the experiences of family caregivers during the transition from hospital to home. The purpose of this investigation was to understand the experiences and perceptions of family caregivers of an individual with TBI during the transition from hospital to home, defined for the purposes of this article as the first 6 months posthospital discharge. It is anticipated that this information will enhance the knowledge base on the transition phase and inform service development to support families during this transition.

Methods

The current qualitative investigation forms part of a larger mixed methods study using a sequential explanatory design (Creswell & Clark, 2007). This mixed methods design incorporates quantitative and qualitative research phases conducted separately in sequential order. Typically, the second phase is used to obtain further detail (or explanation) of a phenomenon or of key findings from phase one. In the current study, phase one was a quantitative prospective longitudinal investigation with data collected from 127 individuals with TBI and 83 family caregivers over the first 6 months postdischarge from hospital (Nalder et al., 2012). Phase two, from which this article is drawn, was a qualitative investigation of participants with TBI and their family caregivers using an interpretative research paradigm. An interpretative paradigm was used as the purpose of the study was to explore the experiences and perceptions of family caregivers during the transition from hospital to home, recognising that individuals construct personal meanings from life experiences (Willis, Jost, & Nilakanta, 2007). Quantitative and qualitative data were connected via the purposive sampling method used for participant selection in the qualitative investigation (phase two) which is the focus of this article.

Participants

A participant selection typology was employed within the sequential explanatory mixed methods design to identify participants for phase two (Creswell & Clark, 2007). Purposive maximum variation sampling (Patton, 1990) was used to develop a sampling matrix identifying 18 individuals with TBI who had either a positive or more negative perception of the overall transition experience (rated on a visual analogue scale) and who had encountered a range of sentinel events (e.g., positive events such as return to work, or more negative events such as financial strain). Identifying individuals with TBI who reported a less successful transition was difficult and thus the final sample included 16 individuals with TBI. At the point of initial consent for phase one, each individual with TBI nominated a family caregiver who was then approached to obtain consent for participation in the research investigation. These caregivers are the focus of this investigation. Of the 16 individuals with TBI participating in phase two, four participants had no family caregiver and two participants' caregivers declined to consent for the second research phase. Therefore, the sample used in this investigation was 10 family caregivers, of which all were female and either a spouse ($n = 6$), parent ($n = 3$), or ex-partner ($n = 1$) of the individual with TBI. Family caregivers were aged between 30 and 62 years (mean = 47.8, $SD = 10.1$), mostly in a relationship ($n = 6$) and employed in paid full-time work ($n = 7$) prior to their relative sustaining a TBI. The two caregivers who declined to consent for phase two were both an ex-partner of the individual with TBI, female and aged 23 and 28 years. Characteristics of individuals with TBI are provided in Table 1.

Data Collection

The project had ethical approval from relevant hospital and university ethics committees. Data collection involved the use of semistructured interviews conducted in person ($n = 4$) or via use of loudspeaker telephone ($n = 6$). Telephone interviews were required due to difficulties with scheduling an

TABLE 1
Characteristics of the Individuals with TBI ($N = 10$)

	mean, *SD* (range), or *n* (%)
Age	38.3, 15.1 (18–55)
Gender	
Male	10 (100%)
Initial GCS	14.4, 4.8 (3–15)
Duration of PTA	18.0, 24.1 (< 1–68)
Length of hospital stay	46.4, 45.0 (4–109)
Cause of injury	
Fall	3 (30%)
MVA	2 (20%)
Pedestrian vs. vehicle	2 (20%)
Other (e.g., assault, surfing accident)	3 (30%)
Pre-injury occupational status	
Paid full-time	9 (90%)
Student	1 (10%)
Geographic location	
Metropolitan	6 (60%)
Rural	4 (40%)
Hospital experience	
Acute	5 (50%)
Rehabilitation	5 (50%)
Perceived transition success	
More successful	7 (70%)
Less successful	3 (30%)
Report of sentinel events	
Generally positive	3 (30%)
Mixture of positive and negative	4 (40%)
Generally negative	3 (30%)

TBI = Traumatic brain injury; SD = Standard deviation; GCS = Glasgow Coma Scale; PTA = Post traumatic amnesia; MVA = Motor vehicle accident.

appointment and/or the remote location of several participants.

All interviews commenced with the open question, ‘how has life been for you and for your family since [individual with TBI] returned home from hospital?’ This key question was designed to encourage discussion about how the caregiver’s life had unfolded during the transition phase. Interviews then followed a flexible series of questions determined on the basis of information provided by participants. Topics relevant to the life course theory were covered, including key events that had influenced their life, environmental factors that helped or hindered their life and their feelings and thoughts about the future. A time line was used as a prompt at the end of interviews to obtain more detail about the experience of sentinel events reported by caregivers during phase one (i.e., the prospective longitudinal study over the first six months postdischarge). Interviews were conducted on average nine months (7–12 months) after the individual with TBI reentered the community, and ranged from 30–145 minutes in duration. All interviews were conducted by the first author, a doctoral candidate and an occupational therapist, who was also involved in data collection during phase one.

Data Analysis

Data were analysed thematically using a framework approach (Ritchie & Lewis, 2003) and guided by the life course theory (Elder & Giele, 2009). A framework approach is a form of thematic analysis in which coded data are organised within a matrix to allow for comparisons within and across participants, aiding in the synthesis of information

TABLE 2

Principles of Life Course Theory

Life course principle	Description
Timing of lives	Importance of investigating the timing of life events or transitions within context of the life course. People coordinate responses to the timing of external events such as loss of employment to undertake actions that use available resources most effectively.
Human agency	Considering individuals motives to satisfy personal needs and their influence on decision-making and therefore the organisation of lives around goals within the constraints of their environment.
Linked lives	The life of a person is interwoven with the lives of significant others.
Historical time and place	Refers to the social, historical and geographical factors that influence human experiences (e.g., social and cultural variations, social hierarchies, and historical events).

Elder, G.H., & Giele, J.Z. (Eds.). (2009). *The craft of life course research*. New York: Guilford Press.

(Ritchie & Lewis, 2003). Four principles of the life course theory (i.e., timing, human agency, linked lives and historical time and place), are relevant to research and were considered during the thematic analysis (Elder & Giele, 2009). Descriptions of these principles are outlined within Table 2.

All interviews were transcribed verbatim and then reread to increase familiarity with the data. A preliminary coding framework was developed based on three key interviews selected by the interviewer according to the types of sentinel events reported by the individuals with TBI, which was a key dimension used in sampling. Life course theory was also guiding development of the coding framework. For example, the life course theory acknowledges that life events, human agency and social and contextual factors can shape expectations for the future life course and, as such, one code was 'caregivers' hopes and expectations for the future'. Peer-checking was then completed to ensure data coding and interpretations accurately reflected interview data. The coding framework was refined by reaching mutual agreement on discrepancies between the two researchers involved in the peer-checking process. One example of refinements to the coding framework was renaming the code 'loss of routine' to 'disrupted routine'. Once all interviews had been coded using the amended framework, higher and lower order themes were developed by examining coded data together in a matrix. For instance, 'protecting the individual with TBI' was identified as one subtheme under a broader and more dominant theme, 'weight of the care responsibility'. A summary of themes was developed and sent to participants for member-checking. One response was received and, as the caregiver was in agreement with the descriptions of all themes, no amendments were made. A second stage of analysis was then conducted using the matrix to compare and contrast the range of caregivers' experiences within the dominant themes. Based on this secondary analysis three subgroups of participants were identified and the findings were then examined within the context of background literature in the area. All data coding was completed using the software program N-Vivo^{TM} Version 9 (QSR International, 2010).

Rigour

Several steps were undertaken to ensure that data collection and analysis were rigorous. All interviews were conducted by the same person, who had established rapport with participants due to involvement in phase one of the research. Peer-checking was completed to ensure data coding was reliable and member-checking was conducted to ensure data analysis accurately reflected the perceptions of family caregivers regarding the transition experience. An audit trail was kept to document all decisions made in theme development.

Results

The life course principle of linked lives was evident in all participants' experiences as an unexpected event (the injury) impacted on the life course of not only the individual who sustained the injury but also their family members who transitioned into the role of caring for an individual with TBI. There was an overarching theme of *wanting to move past the injury* and this was experienced differently by subgroups of participants. Two subthemes, *weight of the caring responsibility* and *wanting normality for the individual with TBI*, provided the context for caregivers seeking to move past the injury. Figure 1 provides a visual representation of themes and subthemes, which are presented in more detail below. Illustrative quotes are provided in the text with the participant number and a letter denoting the speaker (i.e., a 'P' was used for parents, 'S' for a current or ex-spouse and 'I' for the interviewer).

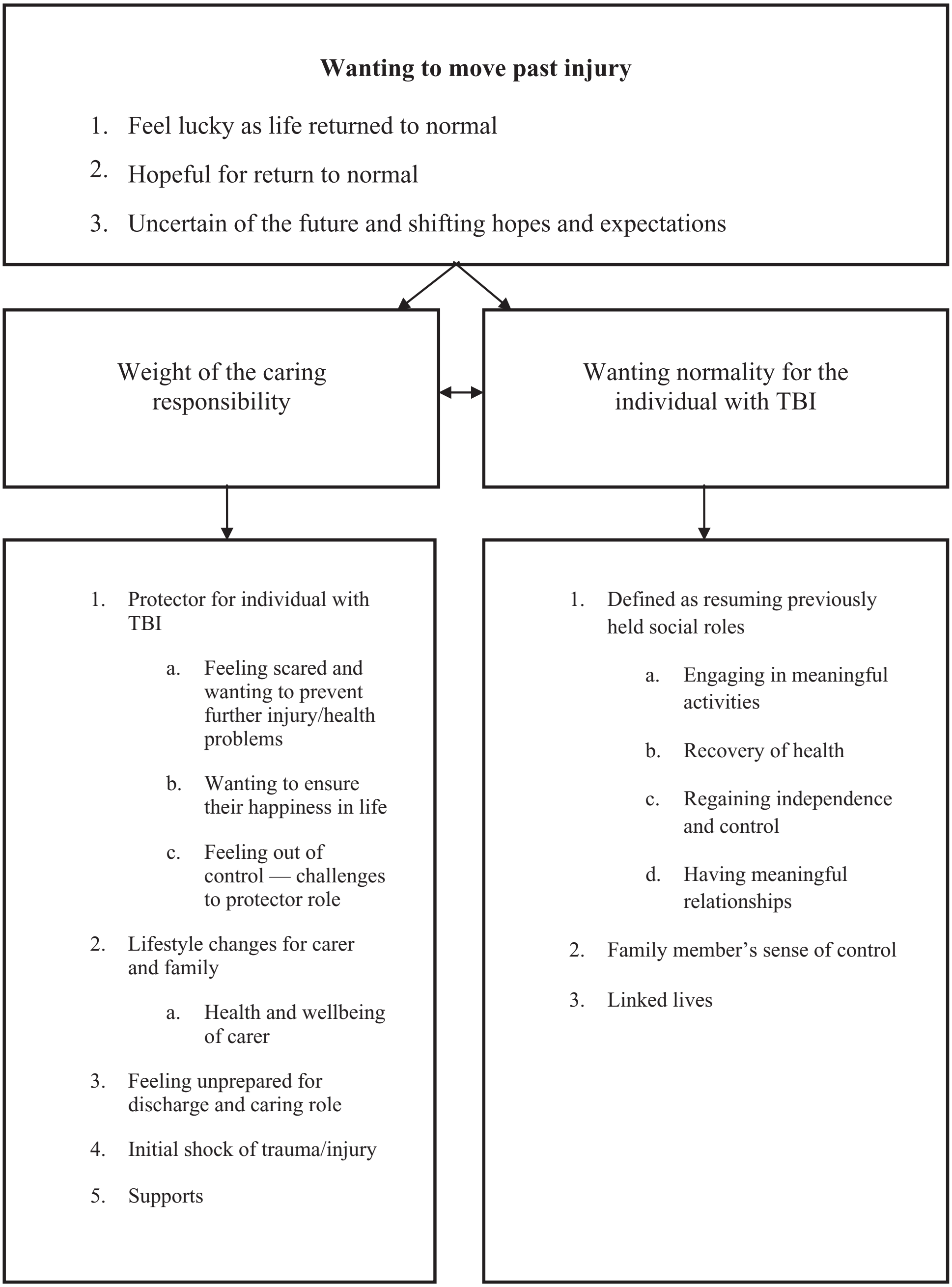

FIGURE 1

Links between dominant themes and their subthemes.

Wanting to Move Past the Injury

During the transition from hospital to home, family caregivers described their hopes and expectations for the future with the overarching theme being *wanting to move past the injury*. Caregivers described wanting to move beyond the negative experiences associated with the injury and move forward with life by resuming the lifestyle and social roles that they and their family members (including the individual with TBI) were engaged in prior to the injury. As can be seen in the following quote, resuming previously held roles such as that of worker was viewed as a marker that the health problems were behind the family and life was resuming.

> *S: Um, but it's, you know, it was good for him to have more, you know, organisation in his life by getting back to work. Picking up the reins again, all that sort of thing. It was like okay, all that's behind us, this is life.*
> *I: So that was a point of sort of moving past do you think?*
> *S: Yeah, it's like a (clears throat), like a end of a race. There's the finish line of that, this is the start of life again, you know.(PA2C047)*

Subgroups of Participants

Three subgroups of caregivers were identified, each distinguished by the degree of hope that the family would successfully *move past the injury*, the *weight of care responsibility* that fell on caregivers and hope for a return to *normality for the individual with TBI.* Family caregivers in this study either felt lucky that life was perceived to have returned to normal ($n = 4$), felt hopeful that life would return to normal ($n = 4$), or were feeling uncertain about the future and in the process of shifting their hopes and expectations ($n = 2$). Typically, those participants in the first subgroup who felt lucky that life had returned to normal experienced a lower weight of care responsibility and greater return to normality for the individual with TBI compared to the other two subgroups.

> *S***:** *Well, we have been, I would have to say we are one of the very lucky ones and we've, after like about four, five months we were able to go back to fairly normal. Yeah, he's one of the very lucky ones.*
> *I: You mentioned going back to normal after about four, five months or so. What, what's normal if you, like what do you mean by that?*
> *S***:** *Well, he could drive again. He was, um and possibly the driving and becoming independent and he could go back and do some casual work to fill in his days. (PA2C063)*

The degree of hope that the individual with TBI could regain a normal life was a key factor differentiating the three subgroups of caregivers wanting to move past the injury. For example, the four caregivers who were in the second group recognised the progress made since discharge and therefore were hopeful of moving past the injury and that their relative with TBI would eventually return to normality. Progress was reflected either in terms of recovery or the ability to resume some former roles. Additionally, these four caregivers viewed aspects of their personality — such as looking at the positives, being able to keep things in perspective and just getting on with what needs to be done — as helping to cope with the weight of responsibility in the caregiver role. These caregivers identified their personality style as assisting in maintaining hope for the future and their ability to continue working towards the desired outcome of return to normality. The following quote illustrates a caregiver hoping for an eventual return to normality and applying strategies to maintain a positive and hopeful perspective on life.

> *S: Um, it's all just milestones I guess. Ah, like even when he was in hospital I had a photo of him when he was driving trucks. It's still on my phone actually. When he was at the mines. And that's where I believe he'll return to. So we just, you know, you don't . . . that's what you're focused on. That's where he was and that's where he'll go back there. And at night time before you go to bed that's the last thing you look at. You try not to focus on what, what is. It's what will be. Where you want it to be. (PARU106)*

Conversely, the two participants in the third subgroup who were feeling uncertain about the future were both experiencing higher levels of emotional distress and described feeling angry or sad with their present life. Both participants described changes in how they felt about their life over the course of the transition period, which stemmed from a progressive increase in the weight of care responsibility, loss of hope for a return to normality and personality and behaviour changes observed in the individual with TBI.

> *P: . . . But we were worried about you know, just him — leaving him if we had to go to work. It was all that sort of stuff but then that sort of passed; that stage passed. He became more aware, he took himself off the medication and he had a good stage there for a while where he was in an in-between stage where he wasn't so confused but he still did not have the energy to want to do much more. So there was a good spot there where it was good. I shouldn't say good should I, because it wasn't normal, but it wasn't so hard and it was easy. And then the last couple of months it has been extremely hard — very hard. As in very demanding . . . very . . . you know showing no concern over how he comes across like to us. Like it is all about him; he is very selfish with what he wants. I guess that is because he wants his life to get*

> *back to how it was and I don't think he can accept that what has happened to him has changed his life. (PARU083)*

Subtheme 1: Weight of the Caring Responsibility

Participants experienced significant changes to their own lives in taking on the caregiver role and the weight of the caring responsibility was the first subtheme driving their desire to move past the injury. This subtheme highlights the experiences of family members as they transitioned into a new caregiving role for an individual with TBI. Participants expressed a willingness to take on the caregiver role and linked this decision to their relationship with the individual with TBI (i.e., something you do as a wife or mother). However, despite the unquestionable commitment to the individual with TBI, caregivers described the pressure entailed in the role and there was a sense that caregivers felt overwhelmed by the responsibility.

In particular, caregivers viewed themself as a *protector for the individual with TBI,* which significantly contributed to feeling a weight of responsibility. Caregivers described feeling scared that their relative with a TBI would experience further injury or health problems, scared that they would not be there if their relative with a TBI needed something and scared of the choices and decisions made by their relative with a TBI. For example, in the following quote the caregiver expresses a desire to protect the individual with TBI in social situations.

> *P: He probably didn't think so but I knew that he had very strong feelings for [ex-girlfriend] so I knew that it would have been so hard for him to be up there and her be there and they weren't talking at that stage and I didn't want him to go out somewhere and for instance her to be in the company of other young people if he got jealous and done something silly. Which I wasn't sure. At any normal time, no I wouldn't have to. I wouldn't think he would do that but I just wasn't sure how he was thinking and I just didn't want him to be put in that situation. So I suppose it was protection. (PARU071)*

These fears were driving a desire to protect the individual from harm and also to help them achieve a sense of normality and happiness in their life. Added responsibilities were placed on caregivers in order to achieve this, including organising and attending medical appointments, driving, supervising the individual with TBI and monitoring their health. The responsibility of protecting the individual with TBI had a bi-directional relationship with the theme wanting normality for the individual with TBI. For instance, part of wanting to protect the individual with TBI was to see them happy and this was often linked to the caregiver's definition of normality. However, as individuals with TBI achieved a greater sense of normality, the caregivers' protective role and, in turn, the weight of the care responsibility reduced, particularly for caregivers in the first subgroup. In the following quote the reassurance of knowing the individual with TBI could be left alone reduced the worry associated with caregiving.

> *S: 'But no, it was good knowing that, you know, he could be left alone and he was perfectly capable of looking after himself, so that was reassuring' (2C072).*

The added responsibility for protecting the individual with TBI meant several caregivers were forced to juggle multiple roles, which added to their perceived pressure and weight of responsibility. Examples of participants juggling roles included balancing the new caregiver requirements for an individual with TBI with other commitments such as work or other care giving responsibilities (e.g., for children or other family members).

> *P: So there was a lot of, I mean it doesn't sound like much to some people but when your whole household changes because of one person it is, it is massive, I mean even [husband] had like, even in the fourth term of the school year, I was working two days a week and having three days off and [husband] was actually taking the two days off when I was at work, so even his, even his work, like he felt like he should be at work but at the same time he felt that he needed to be at home so there was all that sort of stuff. (PA2C018)*

Family caregivers felt that certain factors challenged their ability to protect their relative with a TBI. Specifically, caregivers struggled with the need to protect their relative from further injury, while also acknowledging a need to recognise the individual's independence and allow him or her to carry on with their life.

> *P: They [friends] have just spoke about different stuff they are going to do and that and I have thought no, no I don't want that. And I have thought, but I can't stop it because they are in their 20s and it has really pissed me off because I have thought you really haven't fully understood what [individual with TBI] is about. But then I thought, well I have to let [individual with TBI] learn the hard way. (PARU083)*

In taking on the responsibility for protecting their relative with a TBI, caregivers experienced *lifestyle changes*. The types of lifestyle changes described by participants included changes to their routine, changes in their usual activities (e.g., loss of leisure time and ceasing work), losing their independence (e.g., from financial strain and having to be constantly available to support the individual with

TBI) and experiencing relationship changes (e.g., adjusting to a changed person following the TBI or experiencing separation from a partner). Most perceived the changes negatively and wanted to get past the injury and return to their previous lifestyle. The caring responsibility and lifestyle changes also meant that some participants experienced health problems, most commonly increased feelings of fatigue and emotional distress.

> *P: Everything is just harder. Things get missed. Things don't get done any more. It's tiring; I'm tired. My body . . . you know I don't get to do exercise. I don't get to eat right any more hardly. I'm always sad; I am always on the verge of tears . . . (PARU083)*

Most participants found the weight of responsibility associated with the caregiver role difficult and a stressful adjustment. The transition from hospital to home, and therefore the transition into the caregiver role for an individual with TBI, was perceived to happen quickly and most felt unsure of how to manage the new role. Participants commonly described *feeling unprepared* for this heightened responsibility and doubted their ability to adequately protect or meet the needs of their relative with a TBI.

The experiences of caregivers during the period of hospitalisation were described as chaotic, stressful and characterised by a *feeling of shock* and a need to focus on whether the individual would survive. The anxiety levels of caregivers were heightened as a result of the trauma, which influenced the transition from hospital to home and the manner in which they coped with the caregiver role. For instance, some caregivers described gaining knowledge of their own strength from the experiences in hospital, which they carried into the caregiver role. Conversely, other participants described feeling scared by the information they received in hospital, which served to increase their need to protect the individual with TBI and therefore their perceived burden. In the following quote, the fear associated with taking on a caregiver role causes a negative perception of information provided at hospital discharge and a feeling of being underprepared to provide the required supports to the individual with TBI.

> *P: Well, nobody tells you what . . . nobody tells you anything. Sorry, I shouldn't say it like that. They give you so much . . . negative input on what could happen that you do leave, you do feel scared. You feel like, you know, I suppose in our, in my case it was . . . it was I didn't actually take [individual with TBI] to the hospital straight away. So I was already doubting myself as being a good parent, because I didn't do that. And then for them to say, you know, he's going to come home and these are the sort of things that could happen — seizures, blindness. You know, there was just a whole list of things that could happen, that yeah, I was scared that I would not be capable of reading the signs for these things. (PA2C018)*

The presence of *supports* served to reduce the weight of responsibility on caregivers. Both informal (provided by family and friends) and formal supports (e.g., rehabilitation services, the workplace and financial support schemes) were important. For example, financial supports took a major stress away from caregivers; workplace support provided caregivers with flexibility to juggle their roles; and case management services and the availability of informal supports were perceived to spread the caring responsibilities, reduce the perceived pressure on caregivers and enable them to maintain some of their premorbid roles and lifestyle. This quote illustrates how social support was essential for the spouse to be able to return to work.

> *S: I just didn't like leaving [Individual with TBI] alone even when I went to work mum and dad would come over because they don't live very far. Mum would drop him off a sandwich or something like that um because I just didn't want to leave him by himself you know if he wasn't feeling well or his hand was aching or you know. (PA2C032)*

Subtheme 2: Wanting Normality for the Individual with TBI

A second subtheme associated with moving past the injury was the desire of family caregivers to see the individual with a TBI regain a normal life. Return to normality was defined by family caregivers as the individual *resuming previously held social roles*; in particular, resuming activities such as work, having meaningful relationships and regaining independence. Additionally, recovery of health and functioning following the injury was viewed as an important factor determining whether the person could return to normality. Wanting to see the individual return to normality stemmed from their desire to protect the individual with TBI and see them get past the injury and have a happy and fulfilling life. The following quote illustrates the desire of a parent to see her child have a life that makes him happy and how his premorbid roles are integral to achieving this sense of normality.

> *P: I want to see my son play soccer, with headgear on of course, which is one of the things I have actually said to him. I want to see him jumping up and down on the trampoline, I want to see him running the way he used to, I want to see him out dancing with his friends at a club with the music blaring, and I want to see him drive a car.*
> *I: You want to see him do all those things.*

> *P: I want to see him do all those things again because that's what he was doing before the accident, and I know that it has only been 12 months, but at the end of the day, the more you say to someone you can't do this, they are either going to totally rebel and do it regardless and maybe do some really, really bad things, or they do what [individual with TBI] does and say well you know, I've got nothing to live for. (PA2C018)*

All caregivers desired a return to normality for their relative with TBI; however, it was particularly important for three caregivers, each of whom took on a caring identity and reported losing control of their own life to focus entirely on the needs of their relative.

> *P: But anyway, so his whole life has changed and turned upside down. But it is coming together. Um and then I guess that's where we go to both extremes. Well, in the last six months, it's not about my life. Well actually I have to put [individual with TBI] first. (PARU071)*

Caregivers perceived that a return to normality for the individual with TBI was dependent on several factors out of their *control*, namely the individual and their motivations and recovery, the ability to access rehabilitation services and medical restrictions limiting the resumption of life roles (e.g., that of driver). Family caregivers described feeling sad or frustrated at not being able to help their relative with TBI return to normal as this challenged their innate desire to protect the individual and ensure their happiness.

> *P: That was another thing that his caseworker down here was supposed to arrange was a driving test but she never did. So we just can't hang around and sit around and wait when he has got a life to live and I can't just help him back. He's had 12 months and I know that we are luckier than lot of other families you know. I am so lucky that my boys came through this after this car accident, but you know I can't, I can't just sit around and watch them sitting around waiting for life to go past them. (PARU071)*

Caregivers viewed their own future in terms of what outcome the individual with TBI would be able to achieve. This relates back to the weight of the care responsibility, as caregivers see no end to the caring responsibility and therefore no chance of moving past the injury, unless the individual with TBI were to resume their normal life roles. For example, as long as the individual was unable to drive, caregivers were required to assist with transportation thus influencing their lifestyle and routine. The fact that family caregivers unquestionably link their future to that of the individual with a TBI highlights the life course principle of *linked lives*. The lifelong commitment to supporting the individual with TBI is reflected in the following quote from a parent who describes a journey that she has no option but to continue with at this stage.

> *P: But I know it is a journey and we have no choice but to go through this journey with him as, you know, as his parents. And it is really hard to know the outcome of the journey. We just have to sort of accept what has happened and try to make the best of it. It is really up to [individual with TBI]. (PARU083)*

To summarise, the transition from hospital to home for family caregivers of an individual with TBI is characterised by a hope to move past the negative experiences associated with the injury and return to normal family life. Three subgroups of participants were identified within the sample — those who felt lucky as life returned to normal, those who were hopeful of an eventual return to normality and those who felt uncertain about the future. Individuals feeling lucky typically perceived a lower caring responsibility and the individual with TBI had made greater progress in recovery and resumed more premorbid roles than individuals in the other two subgroups.

Discussion

This investigation highlighted the perspectives of family caregivers regarding the transition phase after return home from hospital following TBI. Caregivers expressed an overall desire to move past the injury, which stemmed from reflections on how their life and the life of their relative with a TBI had changed since the injury. Specifically, the weight of the care responsibility (i.e., changing their lifestyle to protect the individual with TBI) and wanting their relative with a TBI to return to normality (i.e., regain their independence and engage in meaningful activities and relationships) were driving a desire to move past the injury. Three subgroups of participants were identified and were distinguished by the degree of hope caregivers held for successfully moving past the injury. These groups ranged from participants feeling life had returned to normal to participants feeling sad with life and uncertain about the future. The results of this investigation can be contextualised within the life course theory, in relation to literature on caregiver experiences following acquired brain injury and hope.

Life Course Theory

The life course principle of linked lives was evident in all participants' descriptions of the transition experience (Elder & Giele, 2009). This principle reflects the interdependence of human lives (Elder

& Giele, 2009) and was evident as the individual's transition home from hospital, although not directly experienced by the caregiver, resulted in a major transition in the caregivers' life course as they adopted a greater caring responsibility following hospital discharge. Typically, caregivers were committed to adopting this role; however, for many it was difficult and caused them to experience several health and lifestyle changes (e.g., greater emotional distress and giving up work). Further evidence of linked lives was observed in caregivers' hopes for the future as they wanted the individual with TBI to return to normality. In wanting normality, the hopes of caregivers match those of individuals with TBI (Nalder, Fleming, Cornwell, Shields, & Foster, 2011). However, caregivers also linked their own future (i.e., their weight of care responsibility and the ability to move past the injury) to whether the individual with TBI was able to return to a normal life. The concept of linked lives being so prominent in the experiences of family caregivers has important service implications and reinforces a need to support the entire family system during transition to the community (Kreutzer, Stejskal et al., 2009).

Previous literature examining the transition from hospital to home from the perspectives of individuals with ABI demonstrated the presence of several sentinel events, including financial strain, relationship breakdown, accommodation changes, difficulty accessing therapy services, return to work, return to driving and regaining independence at home and in use of transport (Nalder et al., 2012; Turner et al., 2007). Each of these events was associated with caregivers' definitions of normality seen in this study. The fact that caregivers defined normality in terms of social roles highlights the influence of social and cultural expectations regarding the timing of life events and transitions, which is consistent with the life course theory (Elder & Giele, 2009). For instance, entry into the workforce is expected of adults and many caregivers defined return to normality as the point when their relative with a TBI was able to return to work. The occurrence of these sentinel events for individuals with a TBI also served to increase or decrease the weight of the care responsibility, providing further evidence of linked lives. For instance, negative events such as having difficulty accessing therapy services meant caregivers felt unsupported and perceived greater burden, whereas positive events such as regaining independence at home reduced caregiver worry and enabled them to resume some of their premorbid roles such as returning to work. The nature of linked lives between an individual with TBI and their caregiver reinforces a need to monitor the occurrence of sentinel events as they influence the overall transition experience for both the individual and their family caregivers (Nalder et al., 2012).

Elements of human agency were evident in caregivers' experiences, particularly in their decisions surrounding taking on the caregiver role (Elder & Giele, 2009). Caregivers described the importance of looking after people they cared about and therefore felt adopting the caregiver role was a natural decision, based on their relationship to the individual with TBI (Jumisko et al., 2007). Thus, caregivers directed their own life course in response to the environment (i.e., considering the limited options for support persons for the individual with TBI) and in relation to their socialisation and understanding of family roles. The International Classification of Functioning, Disability and Health, recognises the importance of environmental factors to participation (World Health Organization, 2001). The commitment of family members to the caregiver role is an important environmental facilitator for individuals with a TBI. However, caring involves significant responsibility, with at least half of the current sample feeling unsupported and both the current findings and previous research indicating potential for caregivers to experience their own health problems (Marsh et al., 1998). It follows that services should support families to capitalise on their commitment to assisting individuals with TBI and prevent further functional or health problems to both the individuals with TBI and the family caregivers themselves.

To the authors' knowledge, this study provides the first example of research using life course theory to investigate the experiences of family caregivers following TBI. The findings confirm several of the key principles of the theory, including the interdependence of human lives (linked lives) and human agency as integral in explaining life course variations. One of the key findings in this study was that caregivers want to protect the individual with TBI and help them to return to a normal life (e.g., by regaining their independence and resuming valued roles). The conflict described by some caregivers between their agency (working towards regaining normality) and their protective instinct raises an interesting question about how the principle of human agency is applied with this caregiver population; it suggests that other factors in addition to the environment (e.g., life events such as relationship breakdown) may shape human agency.

Caregiver Hope Following ABI

While there has been limited research to date exploring the lived experiences of family caregivers of individuals with ABI that which exists highlights the importance of maintaining hope (Jumisko et al., 2007; Keenan & Joseph, 2010). This was reinforced in the current findings where the main overarching theme ‘wanting to move past the injury’ represented caregivers’ hopes for the future. There are varying definitions of hope in the literature; however, most authors recognise that it is a multidimensional concept, relating to the future, involving personally meaningful goals and the inner motivations that enable people to act towards reaching the desired goal (Bluvol & Ford-Gilboe, 2004; Borneman, Stahl, Ferrell, & Smith, 2002; Cross & Schneider, 2010).

Hope has been linked to quality of life, engagement in rehabilitation, coping styles and emotional wellbeing (Arnaert, Filteau, & Sourial, 2006; Bluvol & Ford-Gilboe, 2004; Gum, Snyder, & Duncan, 2006; Peleg, Barak, Harel, Rochberg, & Hoofien, 2009), which highlights the importance of this concept for rehabilitation professionals. The importance of hope is reflected in the current findings whereby those individuals who felt that life had returned to normal, or perceived themselves to be working towards this goal, also had higher levels of hope. These caregivers were better able to cope with the caring role and had less emotional distress, compared to those who were grieving their former life and feeling uncertain of the future.

Hope is described as always present; however, it changes over time in response to changing circumstances and personal adaption (Arnaert et al., 2006; Bluvol & Ford-Gilboe, 2004). This was evident in the current findings as even the two participants feeling uncertain about the future maintained some hope (albeit at a lower level than other participants). Additionally, while these caregivers were beginning to lose hope that their lives would return to normal (or the way they were prior to the injury), they were in a process of adapting their hopes for the future. This study only considered a short time frame when taking into account family outcomes following TBI. There is a need for further longitudinal research examining lived experiences of family caregivers as feelings of hope may change over time as family circumstances change.

There is clearly a need for services to attempt to maximise hope in family caregivers as hope was observed to influence the manner in which they coped with the caregiver role and their quality of life. Instilling hope in clients and their family members is not always described as a core role of health professionals (Arnaert et al., 2006). Furthermore, conflict can arise between a desire to foster hope in families as well as a desire to adequately prepare families for life changes and avoid encouraging unrealistic expectations. This was evident in the current findings where information provided at discharge, which was intended to prepare families for the transition home, also caused anxiety and perceptions of a larger burden of care. There has been very little research on hope in the ABI population to date and what exists has focused on examining hope from the perspective of the individual, not caregivers (Arnaert et al., 2006; Cross & Schneider, 2010; Gum et al., 2006). Given the important, but challenging, role for professionals in maximising hope in caregivers, further research is needed to examine their experiences of hope and factors they see as enabling them to maintain hope, or adapt their hopes for the future.

Clinical Implications

The key themes in this investigation highlight both the burden experienced by caregivers and their own hopes and expectations for their families’ lives, which have important implications for service delivery and research. Most caregivers in the study felt unsupported and unprepared for this role, which added to feelings of worry. This was the case despite the fact that half of the sample had received inpatient rehabilitation. It is clear, therefore, that a gap exists in the perceived service needs of family caregivers during transition and what is currently provided. Previous research has highlighted that counselling and respite services are important to family caregivers (Rotondi et al., 2007; Turner, Fleming, Ownsworth, & Cornwell, 2010). On the basis of this study that identified the linked lives of caregivers and individuals with TBI, it also appears important to involve family caregivers in the rehabilitation of individuals with TBI as much as possible. Furthermore, as caregivers reported losing hope in response to behaviour changes in the individual with TBI, support and education in this area is also important.

The current findings also demonstrated that all caregivers hope to put the injury behind them and move on with their life. Traditionally, the focus of rehabilitation services is on the individual with TBI and little empirical evidence exists on interventions targeting the family caregiver. Moreover, existing research typically focuses on maximising families’ ability to effectively support the individual with TBI without acknowledging the hopes caregivers have for their own lives, which may have been dramatically altered following the injury (Kreutzer, Stejskal et al., 2009). The willingness of caregivers to adopt this role means they may focus on the needs of the individual with TBI at the expense of their own needs (Rotondi et al., 2007; Turner, Fleming, Ownsworth et al., 2010). Services should therefore address the hopes and expectations of caregivers and facilitate them to retain their own life goals that fall outside the caring responsibility. Given the short time frame considered in this investigation, further research on caregiver experiences in the area of TBI rehabilitation and on hope from the perspective of caregivers would be beneficial to inform rehabilitation service provision to better support family caregivers.

Limitations

The aim of this investigation was to consider the experiences of family caregivers during the transition from hospital to home; however, as qualitative data were collected at one time point and quite soon after the injury, changes in the experiences and expectations of caregivers over time were largely not captured. Given the small amount of qualitative research considering caregiver experiences in the TBI rehabilitation literature further longitudinal qualitative research into caregiver experiences is warranted.

The purposive sampling occurred from one recruitment site, all caregivers were female and all individuals with TBI were male. Thus, further research is needed to determine whether findings can be generalised to other contexts and to a broader sample of caregivers of individuals with TBI. Additionally, information related to the key dimensions used in sampling (perceived transition success and types of sentinel events) were drawn from quantitative data provided by individuals with TBI rather than caregivers. Thus, it is unknown whether the sample of caregivers was representative of individuals perceiving both positive and negative overall transition experiences. Despite this, three subgroups of participants were identified within the sample suggesting a range of transition experiences were captured in the data.

Conducting telephone interviews has some limitations, for example in rapport-building, as the researcher is unable to view participants' body language (Minichiello, Aroni, Timewell, & Alexander, 1995). However, the prolonged engagement of all caregivers in phase one of the research meant that they all had experience participating in telephone interviews and rapport with the interviewer had been established. Furthermore, conducting telephone interviews was more practical in many cases (e.g., due to difficulties with scheduling an appointment). The flexibility associated with offering both face-to-face and telephone interviews may have assisted with participant recruitment.

Conclusion

The transition as an individual with TBI moves home from hospital is significant for family caregivers, who described an unwavering commitment to the caring role and therefore linked their lives to that of the individual with TBI. Caregivers expressed an overarching hope to move past the injury, which arose from feeling the weight of the caring responsibility and from their desire to see the individual with TBI return to normality and live a happy life. Caregivers hoped that the individual would recover and reengage in their former social roles (i.e., return to normality), which would in turn reduce the burden on caregivers and enable them to have a sense of normality in their own life. Given the vital role of family caregivers in supporting an individual with TBI to reenter the community, there is a need for research to review the extent to which caregivers' needs are addressed in rehabilitation. There is a need for support services to address the unique needs of family caregivers to facilitate a more successful transition from hospital to home and therefore transition into the caregiver role.

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