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It is the paper published as:

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Title: Experiences of care: Perspectives of carers of adults with traumatic brain injury.

Journal: International journal of speech language pathology **ISSN:** 1754-9507 1754-9515

Year: 2011

Volume: 13

Issue: 3

Pages: 218-226

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DOI: <http://dx.doi.org/10.3109/17549507.2011.549240>

URL: http://researchoutput.csu.edu.au/R/-?func=dbin-jump-full&object_id=23686&local_base=GEN01-CSU01

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Abstract

This paper describes the results of a survey which explored the experiences of carers when accessing rehabilitative services alongside their family member with a moderate-severe TBI. The 184 carers who completed these surveys reflected retrospectively on the care they received. The results of this study indicated that 61% of respondents recollected accessing inpatient rehabilitation following their acute care. However, following inpatient discharge only 33% of carers reported receiving ongoing services. One quarter of carers stated they received inadequate information while transitioning through their healthcare journey and fewer than 20% of carers recollected receiving any formal support service. The results of this study, showed that as carers transitioned through the healthcare journey with their family member with TBI health services progressively declined. As this occurred carers' satisfaction with services reduced, while their responsibilities for caring increased. This trend is concerning given the needs of carers have been shown to change over time and increase if not addressed. This paper describes both carer experience following TBI in Australia and encourages clinicians to advocate for carers needs when planning and providing rehabilitation services.

Key words: traumatic brain injury, family members, survey methodology, healthcare journey, experiences

Introduction

It is well recognised that those who survive a traumatic brain injury (TBI) are often left with a combination of impairments which impact upon their ability to function productively in their everyday lives. Adapting to these changes following TBI can be extremely difficult, not only for adults with TBI but also for their family. Much of the responsibility for supporting a person with TBI during the years that follow their injury lies with informal caregivers, most usually a spouse or partner (Knight, Devereux, & Godfrey, 1998; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007). The impact upon families providing this care is frequently underestimated (Wells, Dywan, & Dumas, 2005). Family caregiving activities are broad, ranging from help with activities of daily living, such as meal preparation, showering, and getting dressed, to assistance with rehabilitation activities, such as advocacy and cognitive therapy (Degeneffe, 2001).

The extent of care families provide ranges from limited support to pervasive assistance in all areas of the injured adult's life. The process of coping with, adapting to and providing care for the adult with TBI is challenging (Sinnakaruppan & Williams, 2001).

Consideration of the needs of those filling the carer role is essential, given that 80% of adults who survive TBI return to the community and need help from their family for support and care (Albert, Im, Brenner, Smith, & Waxman, 2002). Smith and Smith (2000) and Serio, Kreutzer and Gervasio (1995) found that the length and degree of recovery of a person with TBI is closely associated with the health, stress level and psychological burden of the primary caregiver. Meeting the needs of carers throughout their healthcare journeys are essential given the successful social integration of adults

with TBI is dependent on the conditions they experience after they return to the community (Rotondi, et al., 2007).

Sinnakaruppan and Williams (2001) completed a critical appraisal of the literature relating to the perceived needs of carers of head injured relatives in 2001. As part of their study, they critiqued 13 papers resulting from a comprehensive database search (MEDLINE, EMBASE: Psychiatry, CINAHL and PsychINFO). These authors found that five trends recurred in the 13 studies of carer need. These recurring trends included carers' needs for:

- general information regarding the nature of TBI, its effects, and techniques for adjusting to the impairments sustained by the person with TBI;
- health professionals to answer questions with honesty;
- a plan for the future care for the person with TBI in the event of the carer's death or disablement;
- time to themselves outside the home and carer role; and
- hope for improvement, both in terms of impairment improvement in the person with TBI and a reduction in their caregiving role in future.

In an Australian study of 29 carers, Stebbins and Leung (1998) identified similar trends in carer need. However, this study moved beyond just identifying needs to examining whether the needs of carers of adults with TBI changed through time. Stebbins and Leung used a postal survey based on the Family Needs Questionnaire to compare the changing needs of eight carers whose relative had sustained a TBI less than 2 years prior to the

study, to 21 carers whose relative had sustained their head injury more than 2 years previously. The results of this study indicated that the 'importance ratings' of family needs differed significantly between the two groups. Significantly more needs were reported as being unmet with increased time post-injury. Trends in needs were also noted to change from predominantly medical and professional support needs during the first 2 years to needs based around community, caregiver and family support, financial resources and health information with increased time post-injury. This trend is worrying, given the assertion made by Kreutzer, Gervasio and Camplair (1994) that unmet needs of family caregivers result in feelings of isolation, feeling misunderstood and feeling unsupported. The findings of Stebbins and Leung have important ramifications, as they show that carers' needs increase and change over time. Therefore, it is likely that lifelong support for the families of people with TBI is needed. This is an important initial Australian study evaluating changes in carer need over time. However, it does not describe carers' experience of healthcare following brain injury or how their experience this may impact on their needs.

A qualitative study completed by Turner et al. (2007) explored part of this issue in their review of the transitional experiences of 13 individuals with acquired brain injury (ABI) and 11 of their caregivers. The results of the Turner et al. study indicated that during the transition from hospital to home, the psychosocial functioning of adults with ABI appeared to decline. This was reportedly due to greater self-awareness of deficits of the adults with TBI which impacted upon their ability to engage in meaningful tasks. As a

result of their study Turner et al. advocated for improved access to therapy services for adults with ABI and their carers during transitional phases.

Another study targeting consumers' experiences of healthcare and how this impacts on their needs was employed by Rotondi, Sinkule, Balzer, Harris and Moldovan (2007). This US based study, also qualitative in nature, had a much larger participant base (80 adults with TBI and 85 carers). Semi-structured interviews were employed by the authors in this study to ascertain participants' "frustrations, feelings, good and bad experiences, problems, surprises and worries" (p. 18) with their acute care, inpatient rehabilitation, return home and post return home phases of care. Overall, the results of this study indicated that participants' outcome (both those with TBI and their carers) once they returned home was detrimentally affected by insufficient education throughout their healthcare journey and a lack of preparation for the future (i.e., life planning and community integration).

Understanding the experiences and progression of needs of adults with TBI and their carers is an important step towards the development of targeted interventions and services that can meet specific needs at each phase, and better prepare carers for the problems they may face upon client discharge (Rotondi, et al., 2007). Currently, the experiences of Australian carers as they transition through the continuum of care are unknown. The way their experiences shape their needs is also unknown. Turner et al. (2007) has in part explored carers' experience of their transitions from hospital to home and how their lived experiences reflected their need. However, it is the aim of this article

to build on the Turner et al. study to present carers' access to, experiences of and satisfaction with care throughout the whole healthcare journey following their family member/friends' TBI. In describing these experiences this paper aims to provide recommendations to assist clinicians to target the needs of carers throughout the continuum.

Method

Data utilised in this paper were collected from a larger mixed methods project entitled "An investigation of the continuum of care experienced by people with traumatic brain injuries and their families in Victoria, Australia." The methods of this project have been described in detail elsewhere (O'Callaghan, McAllister, & Wilson, 2010). Briefly, this project involved two stages. The first stage implemented two state-wide surveys. Survey one targeted adults with TBI and the second, targeted their carers. The second stage of the project involved in-depth interviewing. Participants were 17 people with TBI and their carers. The data presented in this paper reflect the results of the first stage of this research from the perspective of carers of adults with TBI.

Participants

Individuals targeted for inclusion were the Victorian carers of those with TBI, aged between 16-65 years, who had undergone initial acute care at one of two major Australian trauma centres between July 2001 and June 2005. June 2005 was selected as the latest acute admission date to ensure participants had the opportunity to complete their continuum of care and experience of life back in the community before taking part in the

research. Of the 1,771 eligible individuals invited to take part in this research 202 adults with TBI (see Table I for characteristics) and 184 carers responded. A response rate of 10.4%.

INSERT TABLE I HERE

The majority of carers in this study were female (79%) and were either a family member (55%) or a partner (40%) of the adult with TBI. Most were aged between 46 and 55 years (41%), married (65%) and of Caucasian descent (83%). Many were employed (66%) and had completed mandatory high school requirements (39%) or had TAFE qualifications (30%). The characteristics of carers in this group were similar to those of the participant groups of other studies investigating carer experiences (Ergh, Rapport, Coleman, & Hanks, 2002; Knight, et al., 1998; Machamer, Temkin, & Dikmen, 2002; Marsh, Kersel, Havill, & Sleigh, 1998; Ponsford, Olver, Ponsford, & Nelms, 2003).

Instrument

The research questionnaire was devised by the first author, and based upon clinical experience, an extensive literature review and consultation with specialist TBI services. This survey was specifically formulated to collect information on, and survey opinions of, participants with regard to the recollected care they experienced. The survey was divided into five sections, representing each stage of their continuum of care. These sections were named as follows: acute medical care, rehabilitation while in hospital, leaving rehabilitation in the hospital, after discharge from hospital and personal

information. The survey was comprised of 52 questions distributed across 11 pages. The items included in the survey took open and closed ended forms. All items included within this survey were researched in order to determine their purpose, necessity and accuracy, and were piloted to determine their content validity. Questionnaires were piloted firstly with allied health therapists working within two specialised traumatic brain injury units in Australia and then with ex-clients with TBI and their families within their homes. The researchers were present on all piloting occasions to receive feedback and to modify the questions as needed. The items in the questionnaire were directly pertinent to participants' experiences. The items probed participants' experiences based on recommendations of care as stipulated in clinical care guidelines (British Society of Rehabilitation Medicine & Royal College of Physicians, 2003; New Zealand Guidelines Group, 2006). In this way the research tool demonstrated internal consistency and content validity (forms of reliability and validity).

Data collection and analysis

Data were collected through one postal survey, sent twice. The survey was first sent with an accompanying easy to read information sheet explaining the purpose of the research, its benefits, issues of confidentiality, the time taken to complete the survey, and the investigators' and ethics committees' contact details. Four weeks after the initial mail out, follow-up letters were sent to participants. The need for follow-up letters was established because fewer than 30% of potential participants responded. These follow-up letters were accompanied by another copy of the survey. The follow-up letters reiterated the importance of the research and thanked those that had already replied. All self-

administered surveys were returned via pre-paid envelopes. Return of the survey was taken as an indication of voluntary consent to participate.

Data arising from the survey were entered into a spreadsheet and analysed using the Statistical Package for the Social Sciences (SPSS) and QSR NVivo 7. Analysis of closed-ended questions using SPSS contained descriptive statistics (i.e., frequency and percentage distributions, measures of central tendency and cross tabs) to describe the experiences of carers throughout the continuum of care. Open-ended questions were coded using NVivo to identify common ideas. The coding process used in this stage was consistent with a content analysis procedure in that responses were coded into descriptive categories (as described by Miles and Huberman, 1994). Content analysis differs from thematic analysis in that the major categories are determined before coding. However, new codes were also developed in response to new trends emerging in the data

Results

All results in this section relate to the descriptive analysis of closed ended questions unless otherwise stated.

Access to Care As Observed by Carer

Of those who responded to this study, 113 carers (61%) reported that their family member or friend with TBI accessed inpatient rehabilitation; yet only 60 carers (33%) reported their family member or friend had access to ongoing therapy following discharge (see Table IIa). Of the 113 carers in this study who observed their family

member access inpatient rehabilitation, only 72% recollected that this service was provided by neurorehabilitative experts (see Table IIa). One quarter of carers who accessed inpatient rehabilitation reported that they received inadequate information about their family member's or friend's injury, prognosis and services available post discharge (see Table IIb).

INSERT TABLE II

Degree of Satisfaction with Care As Observed by Carers

Regardless of the level of access to healthcare services, the majority of carers (61%) were either extremely happy or very happy with the care provided in inpatient rehabilitation (see Table III). This level of happiness was noted to drop (39%) when carers reflected on the services provided in outpatient settings.

INSERT TABLE III

Participants listed reasons for their degree of happiness (see Table IV). Patterns in responses (open-ended question) analysed via content analysis suggested that carers' degree of happiness was dependent upon their degree of satisfaction with the level of care provided, the perceived competence of staff, knowledge of and involvement in rehabilitation, perceived client improvement, presence of transitional planning and access to support.

INSERT TABLE IV HERE

Satisfaction with Level of Supports Available to Carers

The majority of carers (74%) in this study reported that they did not receive or thought they were ineligible to receive any form of carer's allowance (see Table Va). Of the 25 participants who reported receiving a carers' allowance, 23 reported that it was provided by social security, with the other two stating that a compensable fund paid their allowance (see Table Vb). Another source of support examined in this study was carers' access to carer support services on client discharge. Only 19% of the carers who responded to this questionnaire reported having access to such a service (see Table Vc). However, 35% reported that they were not the family members or friends primary carer on their discharge and therefore were ineligible for this service.

INSERT TABLE V

Fewer than 20% of carers in this study reported accessing any form of formal support (e.g., carer's allowance, accommodation or travel support (see Table VI) or carer support services) during their family member's or friend's healthcare journey. The reasons for this limited access are unknown.

INSERT TABLE VI

Discharge Planning

Seventy eight percent of carers reported that they were informed of their family member's or friend's discharge the day prior to it occurring (Table VIIa). Furthermore, 66% of carers perceived that the discharge date set for the person with TBI was

appropriate. However, 17% of carers perceived that the discharge date was too early and 5% perceived it was too late.

Of the 113 carers who reported that their family member or friend attended inpatient rehabilitation, 62% reported that they received carer training prior to discharge (see Table VIIIb). On discharge, 53% of carers were given a care plan. The other 47% of carers reported they did not receive a care plan or had never heard of them. Of the 60 carers who received a care plan, 87% found it helpful in instructing them how to care for their family member or friend on discharge.

INSERT TABLE VII

Over 70% of carers in this study reported feeling anxious on client discharge (see VIIc). Reasons for this anxiety (identified in an open-ended question and analysed using content analysis (see Table VIII)) included uncertainty about what life would be like once at home, the degree of caring demands placed on the family once at home, uncertainty about the client's prognosis and the ability of the family to cope, as well as the family feeling ill informed and ill equipped to deal with the "new person". Carers thought that this anxiety could be relieved through greater access to support services, the provision of more information, increased staffing in order to provide services needed by clients with TBI, improved transition planning, improved monitoring following discharge from hospital-based rehabilitation services and decreased demands on carers following client discharge.

INSERT TABLE VIII

Only fifty percent of carers reported they felt they were supported upon client discharge (see Table IX). One hundred and twenty one carers (66%) reported that they were provided with the inpatient hospital's contact details and 109 (59%) reported that they were informed of the discharge services to be provided to both themselves and their family member or friend to ensure continued rehabilitation gains and a smooth transition.

INSERT TABLE IX

Discussion

According to the recollections of carers, access to services for participants with TBI dropped as they progressed through inpatient rehabilitation and community-based settings. This progressive decline in access to services co-occurred with a steady reduction in satisfaction with care through inpatient rehabilitation and community-based rehabilitation services.

The varying degrees of satisfaction reported with residential (i.e., inpatient) versus non-residential (i.e., outpatient) rehabilitation services is not unique to this study. A Canadian study (LeFebvre, Pelchat, Swaine, Gelinas, & Levert, 2005) reported similar findings. According to the results of that study, the majority of adults with TBI and their families were content with services during the acute care and inpatient rehabilitation phases. However, their degree of contentment changed when they returned home. At this stage of the continuum, all adults with TBI and their families criticised the lack of resources (LeFebvre, et al., 2005). These reasons given by carers for their degree of satisfaction with services in this study included the level of information and quality of care provided, satisfaction with transition through continuum of care stages, happiness with perceived

degree of communication between and within services, happiness with perceived staff competence, and satisfaction with service availability.

The perception of a lack of information was the key reason identified by carers which affected satisfaction with services in this study. The lack of information provided throughout the continuum is one of the most frequently cited problems in studies reflecting the experiences of carers (Fyffe, 1996; LeFebvre, et al., 2005; Murray, Maslany, & Jeffery, 2006; Sample & Darragh, 1998). According to LeFebvre et al. (2005), communication and sharing of information by family members, adults with TBI, physicians and health professionals is needed in each stage of the care process. However, health professionals and physicians report that, although it is important to provide family members with information, they are justified in the vague nature of that provision, given “uncertainty about the clinical evolution of the casualty, as well as worries about upsetting the family unnecessarily and, conversely, not giving false hope” about recovery (LeFebvre, et al., 2005). This perception by health professionals and physicians is incongruent with the Victorian Charter of Patient Rights (Department of Human Services, 1995), which stipulates that patients have the right to information about their healthcare, information about which hospital staff member provides their care, and access to their health record if requested.

In their study of carer experience, Knight et al. (1998) reported that nearly all of their 52 participants expressed concerns about how difficult it could be to obtain information regarding appropriate resources for adults with TBI and about the long term

consequences of TBI. In that study, one carer commented that the assistance she most needed was “to be told what to expect and where to go for help” (Knight, et al., 1998). The needs of carers in this study mirrored the findings from the Knight et al. US based study.

Three additional hypotheses as to why carers’ satisfaction levels drop as they transition through their healthcare journey are proposed. The first is that, as people move through their continuum of care, time passes and the rate of spontaneous recovery from secondary impairments drops. Therefore, carers, as well as participants with TBI, may begin to acknowledge their impairments and become frustrated that services cannot “fix” or “cure” them. Secondly, as people move through their continuum of care, the intensity and frequency of services initially provided in acute care slowly lessens. Those with limited knowledge of the health system may become frustrated, not understanding why service intensity reduces. A third reason is that consumers may perceive services are too infrequent to meet their needs as an outpatient or that the quality of the service they receive is compromised. Consequently, it may appear that, as consumers are coming to terms with the impairments secondary to head injury, services are reducing. This may result in the decrease in satisfaction with services noted by participants with TBI and their carers throughout the continuum of care. Further research needs to be conducted in this area to examine these possibilities further.

Additional findings in this study highlighted the high levels of anxiety experienced by carers on client discharge. Reasons for carer anxiety were cited including uncertainty

about what life would be like, the degree of caring required, their family member's likely prognosis and their ability to cope. Solutions proposed to relieve anxiety included greater access to support services, the provision of more information, increased staffing in order to provide services needed, improved transition planning, and improved monitoring following discharge and decreased demands on carers. Social support has been shown to be a moderator of carer anxiety and resultant stress (Ergh, et al., 2002). In their study of the predictors of carer and family functioning following TBI, Ergh et al. found that social support showed a direct and linear relationship to family functioning. In the absence of adequate support, carer stress was noted to increase alongside time post-injury, cognitive dysfunction and lack of insight of deficits in the person with TBI, whereas these characteristics were not associated with distress among carers with perceived adequate support.

The high levels of anxiety of carers upon the discharge of their family member/friend may be due in part due to the poor degree of support, both financially and emotionally, reportedly available to carers upon the discharge of their family member/friend with TBI. In addition, carers taking part in this study reported low levels of access to carer's allowances, accommodation and travel support, and carer support services throughout their healthcare journey. Given the low degree of uptake reported in this study, it appears that support services for carers need to be more readily available or marketed to a greater extent, so that those services available will be utilised when needed.

According to international clinical care guidelines, the provision of early and ongoing support for families of adults with TBI is essential in helping prepare them for the effects of the TBI. Support has also been suggested to reduce the psychological sequelae experienced by the family and result in better long-term outcomes for both the person with TBI and the family (New Zealand Guidelines Group, 2006).

In discussing the findings from this study, the authors acknowledge there were a number of limitations which impact upon the interpretation of its results. These include the low response rate to the surveys employed as well as the fact that the findings reported are based on perceptions. The low response rate (10.4%) to the survey limits the generalisability of this research. Nevertheless, according to Nabors, Seacat and Rosenthal (2002, p. 1043) a response rate of “approximately 15% is comparable to other mail surveys of clinical populations.” There were a number of possible reasons to account for the poor response rate in this study. These include the fact that questionnaires were disseminated from participants’ acute treating hospital. Therefore, the addresses to which questionnaires were sent were written on participants’ initial admission paperwork, up to 7 years prior. The questionnaires were literacy-based; therefore, carers with low literacy levels may not have been able to complete them. The length of questionnaires (6 pages, double sided) could have deterred potential participants. The fact that questionnaires were sent to the address of the adult with TBI, who then decided whether they wanted their carers to respond also impacted upon the potential response rate as the adults with TBI acting as gatekeepers. Finally, 230 (13%) questionnaires were returned unopened. This meant that 184 carers responded out of a possible 1,541, a response rate of 12%.

The findings here reflect the experiences of carers of adults with TBI when accessing their healthcare journey. These experiences are based on participants' perceptions of the events that occurred and do not necessarily reflect the reality of services provided. Nevertheless, current research relative to health outcomes recognises that positive consumer perceptions of services may be more important than current enacted services. For example, Ergh et al. (2002) found that perceived support was more beneficial for consumers following TBI than enacted support, where enacted support referred to the actual helping behaviours and perceived social support referred to an individual's cognitive appraisal of his/her social connections. This research indicates that if carers perceive they are supported, it may be as beneficial as, if not more so than, actual helping behaviours. Therefore, when providing or planning the provision of health services for carers' of adults with TBI clinicians must consider their carers perceptions of experience and need as these they may make the biggest difference to ultimate outcome.

Conclusion

Understanding and incorporating the needs and perspectives of carers can often be a challenge for clinicians when planning for and providing healthcare services to adults with TBI (Rotondi, et al., 2007). Yet ultimately, the recovery of an adult with TBI is associated with the health, stress and burden levels of their primary carer (Serio, et al., 1995; Smith & Smith, 2000) and given that 80% of adults who survive TBI return to the community and need help from their family for support and care (Albert, et al., 2002), clinicians cannot afford to ignore this challenge.

One way to overcome this challenge is for clinicians to dedicate the time to adequately determine the service and support needs of carers during all phases of the care of adults with TBI (i.e., acute, inpatient, outpatient and community based). The aim of this study was to identify the current experiences and needs of carers of adults with TBI in Victoria, Australia. Once clinicians understand these needs, and their progression, they may begin to consider how interventions and services can be put in place to better prepare carers for the problems they are likely to face.

The findings from this study suggest clinicians should consider: providing honest, understandable and complete written and verbal information to carers about injuries, their sequelae and possible services available throughout the whole healthcare journey; providing or sourcing ongoing emotional, psychological and financial support for carers; and provide anticipatory guidance to carers prior to client discharge from hospital and ensure adequate supports are available throughout this transition.

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Tables

Table I. Traumatic Brain Injury (TBI) Onset Information Reported by Participants with TBI (n = 202)

TBI onset information reported by participants with TBI	Numbers	Percentage
Age at onset		
< 18 years	21	10.4
19-25 years	50	24.8
26-35 years	40	19.8
36-45 years	33	16.3
46-55 years	46	22.8
56-65 years	12	5.9
Cause of TBI		
Motor vehicle accident	78	38.6
Motor bike accident	31	15.3
Fall	35	17.3
Assault	15	7.4
Other	43	21.3
Reported severity of TBI		
Mild	28	13.9
Moderate	32	15.8
Severe	65	32.2
Very severe	70	34.7
Missing data	7	3.5

Table II. Carers' Recollections of Access to Rehabilitation Services and Adequacy of Information While in Inpatient Rehabilitation.

	Yes		No		Don't know	
	n	%	n	%	n	%
(a) Carers' Recollections of Access to Rehabilitation (n = 184)						
Inpatient Rehabilitation	113	61.4	69	37.5	2	1.1
Specialist rehab (n = 113)	81	71.7	18	15.9	14	12.4
Ongoing reviews following discharge	60	32.6	109	59.2	15	8.2
(b) Adequacy of Information in Inpatient Rehabilitation (n = 113)						
Information on progress	82	72.6	31	27.4		
General information	84	74.3	29	25.7		

Table III. Carers' Degree of Satisfaction with Level of Care Provided

Satisfaction with level of care provided	Inpatient rehabilitation (n = 113)		Outpatient services (n = 184)	
	n	%	n	%
Extremely unhappy	8	7.1	11	6.1
Not happy	5	4.4	20	10.9
Okay	31	27.4	60	32.6
Very happy	40	35.4	54	29.3
Extremely happy	29	25.7	18	9.8
Missing data	0	0.0	21	11.4

Note: Although only 60 carers reported that participants with TBI accessed formal outpatient rehabilitation, all carers reported accessing some form of outpatient service (i.e., meeting with general practitioner). Therefore, all carers responded to this question.

Table IV. Reasons Given by Significant Others for Satisfaction with Services

Reasons and examples	Inpt. Rehab	Outpt. Rehab
Degree of happiness with level of information provided	5	12
Degree of happiness with general level of care provided	7	8
Degree of happiness with changes in care during transition through acute wards (i.e., movement from emergency → Intensive Care Unit → neurosurgery ward)	1	0
Degree of perceived communication between and within services	2	3
Degree of concerns regarding staff knowledge of TBI	5	6
Mention of impact of staff on recovery of person with TBI	4	0
Greater need for empathy for both the family and person with TBI	0	2
Perceived shortage of services	8	10
Need to respect for the rights of adults with TBI and their families	2	2
Improvements needed in infrastructure	6	2
Need for more transparent and organised transition planning between continuum of care stages	3	4
Happiness with degree of monitoring and follow-up post discharge from residential services	0	19
Impact of location on service provision and ability to access services	3	4
Demand placed upon carers	0	0
Level of anxiety related to uncertainty in client outcome	1	0
Degree to which the needs of significant others were met	5	12
Improved and more transparent funding arrangements	1	9

Table V. Carers' Access to Carer's Allowance

	Number	Percentage
(a) Supports Accessed (n = 184)		
Accessed	25	13.6
Didn't access	136	73.9
Don't know	18	9.8
Missing data	2	1.1
Not applicable ^α	3	1.6
(b) Organisation That Provided Funding (n = 25)		
Centrelink	23	92.0
Traffic Accident Commission	2	8.0
WorkCover	0	0.0
Motor Accident Authority	0	0.0
Other	0	0.0
(c) Carer's Access to Carer Support Services		
Accessed	34	18.5
Did not access	71	38.6
I am not a carer	64	34.8
Missing data	15	8.2

^α If the significant other responding to this question was a professional carer or a person unfamiliar with the healthcare journey of the participant with Traumatic Brain Injury. Their missing response was coded as not applicable.

Table VI. Carers' Access to Accommodation and Travel Support During Inpatient Rehabilitation (n = 113)

	Accommodation		Travel	
	n	%	n	%
Accessed support	13	11.5	15	13.3
Didn't access support, but I would have liked it	26	23.0	46	40.7
Didn't access support, I did not need it	74	65.5	52	46.0

Table VII. Carers' Experiences of Participants' Discharge Timing, Access to Carer Training and Level of Anxiety on Discharge.

	Number	Percentage
(a) Carers' Experiences of Participants' Discharge Timing (n = 184)		
Informed regarding discharge date		
Informed	144	78.3
Not informed	19	10.3
Missing data	21	11.4
Perceived appropriateness of discharge timing		
Appropriate timing	121	65.8
Not appropriate, it was too early	32	17.4
Not appropriate, it could have been earlier	9	4.9
Missing data	22	12.0
(b) Carers Trained to Care for Participant with Traumatic Brain Injury upon Discharge (n = 113)		
Trained to care for client on discharge		
Yes	70	61.9
No	31	27.4
I wasn't trained the carers were	12	10.6
Given care plan on discharge		
Given care plan	60	53.0
Not given care plan	14	12.3
Didn't get one, I've never heard of care plans	39	34.5
Perceived helpfulness of care plan (n = 60)		
Yes	52	86.7
No	6	10.0
(c) Carers' Feelings of Anxiety on Participant's Discharge (n = 184)		
Felt anxious	130	70.7
Did not feel anxious	34	18.5
Missing data	20	10.9

Table VIII. Reasons for Significant Others' Level of Anxiety on Discharge

Reasons for anxiety	No. of references made
Anxiety related to uncertainty for the future	45
Demands on carers to provide care for client	24
Changed person due to TBI sequelae	12
Need for greater information	10
Uncertainty regarding appropriateness of discharge timing	10
Need for support on client discharge	7
Client outcome related concerns	6
Ways anxiety can be relieved, and examples	
Increased support for carers	18
More information needed	16
Relieve anxiety related to uncertainty for the future	4
Relieve staff shortages to ensure adults with TBI get services they need	4
Improved transition planning between continuum of care stages	4
Education regarding changed person due to TBI sequelae and possible implications of this	3
Lessen demands on carers	3

Table XI. Carers' Support on Participant's Discharge (n = 184)

	Support on discharge		Hospital contact details		Informed of discharge services	
	n	%	n	%	n	%
Accessed	91	49.5	121	65.8	109	59.2
Did not access	65	35.3	42	22.8	54	29.3
Missing data	28	15.2	21	11.4	21	11.4