Healthcare Consumers’ Need for Brain-injury Services: The Critical Importance of Timing in Planning Future Services

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Developing an awareness of the preferences of healthcare consumers is essential in determining the ‘reality’ of service provision, in planning the provision of brain-injury services and in service evaluation. Consumers should be given the opportunity to express satisfaction or dissatisfaction with the services they receive, offering their perceptions of barriers to service access, which could be removed once known. This article presents narratives of the healthcare journeys of three adults with a moderate to severe brain injury. The experiences of these participants were elicited through in-depth interviews. The aim of this article is to convey how the needs and experiences of adults with brain injury change throughout time, affecting their ability to access care over time. Previous research by the authors of this paper identified five factors that affect consumers’ experiences of care: acceptance and readiness, support, advocacy, the right service at the right time and mismatched expectations. The fluidity and interaction of these factors through time is demonstrated in this article as facilitating and impeding access to services. The implications for clinicians in considering these factors when planning services for adults with moderate to severe brain injuries are explored.

Keywords: rehabilitation, consumers’ preferences, best practice, timing

Introduction

Researchers worldwide have identified that participation in rehabilitation is one of the key variables shown to improve an adult’s prognosis following brain injury (Cicerone, Mott, Azulay, & Friel, 2004; Goranson, Graves, Allison, & La Freniere, 2003; Malec, 2001; Seale et al., 2002). Intensive rehabilitation following acute medical care has been shown to affect positively community integration and return to work. It has been acknowledged that brain injury rehabilitation requires the close collaboration of many neurological rehabilitation specialists, as an adult’s physical, cognitive and behavioural sequelae cross professional boundaries and require a unified, integrated approach to treatment that extends beyond the rehabilitation clinic into the person’s home and community (Brookshire, 2003).

There are many published national and international clinical care guidelines that stipulate appropriate levels of service provision throughout the continuum of care of adults with brain injury (Accident Rehabilitation and Compensation Insurance Corporation & National Health Committee, 1998; British Society of Rehabilitation Medicine & Royal College of Physicians, 2003; Turner-Stokes, Disler, Nair, & Wade, 2005; Youse, Le, Cannizzaro, & Coelho, 2002). According to these...
Acute care stage

Residential rehabilitation stage
  Inpatient rehabilitation

Non-residential rehabilitation stage
  Outpatient rehabilitation/Community based rehabilitation

Longer-term community support

Reassess as required

FIGURE 1

guidelines, rehabilitation following a brain injury is typically provided in four stages (see Figure 1).

The implementation of these guidelines in the rehabilitation of adults with brain injury helps to standardise service delivery by ensuring the development of equitable and efficient services through the implementation of best practice. However, it is imperative to recognise that the provision of a health service does not guarantee that those who need the service will use it (Humphreys, Mathews-Cowey, & Weinand, 1997). In order for a health service to be utilised, consumer preferences must be considered. Advocacy and regulatory agencies (e.g., National Rural Health Policy Forum, 1999), along with researchers, have acknowledged the vital role healthcare consumers play in the improvement of health services in Australia. Consumers’ preferences for, and experiences of, the delivery of health services have been explored in the literature (Blight, 1991; Brown, 1991; Humphreys & Rolley, 1993; Keleher, 1999). Factors underpinning consumer preferences and experiences of medical services have been identified (Humphreys et al., 1997; Rankin, Newell, Sanson-Fisher, & Girgis, 2000). They include availability (i.e., the existence of services relevant to consumers’ needs), accessibility (measured in terms of distance, time, cost and availability of transport), accommodation (i.e., how the service is organised to accept consumers, measured in ways such as waiting time), affordability (in terms of economic access to services) and acceptability (in terms of consumers’ attitudes towards a particular service or health professional) (Penchansky & William Thomas, 1981).
Canadian researchers LeFebvre, Pelchat, Swaine, Gelinas, and Levert (2005) used semi-structured interviews to investigate the experiences of eight individuals who had sustained a brain injury, their families (n = 8) and the physicians (n = 9) and health professionals (n = 22) involved in their care. This study reviewed the experiences of consumers from acute care management through to their subsequent rehabilitation. LeFebvre et al. (2005) found that the majority of participants were satisfied with the availability of services during the acute care phase. However, satisfaction declined once the adults with brain injury and their families returned home. The adults with brain injury and their families criticised the lack of resources available to them after discharge from residential care. They voiced their belief that the lack of human resources available resulted in exhaustion among professionals, which compromised the quality of care for the recipients of brain injury services. The opinions of physicians and health professionals mirrored patients’ and families’ comments in this study.

The findings of Muus, Cogan, Offutt, and Medalen (2006) were consistent with those of LeFebvre et al. (2005). Muus et al. surveyed 117 North Dakotans with brain injury to identify the major barriers to accessing health and social services from the perspectives of healthcare consumers. They found that the commonly cited barriers to access and service utilisation were shortage of brain-injury advocates, inadequate knowledge of available services, no centralised source of information, inadequate financial resources and lack of individualisation of brain-injury programmes. Although they stated that the majority of barriers experienced were due to poor advocacy efforts and a lack of information, they also reported that many of the cited barriers could be lessened or alleviated through increased effort at the state level to address the needs of people with brain injury.

Another survey of brain-injury consumers’ preferences for, experiences of and satisfaction with services was conducted by the Medical Research Institute of New Zealand (McNaughton, 2004). The aim of this and a second related survey of brain-injury service providers was to allow comparison of international best practice as described in brain-injury guidelines with brain-injury service provision in New Zealand. The responses of 420 adults with brain injury (response rate of 21%) were analysed as part of the New Zealand study. The results indicated that a large number of consumers (40%) were not satisfied with the services that were provided. Gaps identified in service provision included: a perceived lack of knowledge of brain injury among service providers, which affected the way adults with brain injury were treated; difficulty finding available services, which were often self-sourced rather than offered or suggested by service providers; fragmented and/or poorly coordinated services; poor access to services, which appeared to be compounded by degree of rurality; preference for perceived specialist services even if required to travel; variable case-manager services with high staff turnover; and the perception that the New Zealand health system was geared toward the resolution of physical injuries, not remediation of cognitive, emotional or lasting impairments commonly experienced by those with brain injury.

O’Callaghan, McAllister, and Wilson (2009, 2010, 2011, 2012) analysed 386 surveys and 17 in-depth interviews to identify the experiences of Victorian healthcare consumers when accessing care after an acute brain injury. This study employed mixed methods and reflected on the experiences of 202 adults with a moderate to severe brain injury and 184 significant others. The results from surveys indicated that very few participants (20%) reported receiving health services in line with international clinical care guidelines. Participants reported significant gaps in service provision, including lack of specialist services, limited involvement in guiding their care, poor monitoring following discharge from formal services, limited involvement in transition planning, variations in access to care according to funding, and poor access to support upon community integration after discharge from formal services. Interestingly though, those with brain injury and their significant others were largely satisfied with the services received (see O’Callaghan et al., 2010, 2011 for more detail).

In the interviews completed with adults with brain injury and their significant others, five factors were identified which influenced consumers’ ability to access services over time. These factors included: (a) their acceptance of head injury and readiness to engage in therapy; (b) their ability to access constant support; (c) their and others’ roles in advocating for services; (d) their ability to access the right service at the right time; and (e) the degree of match between their and others’ expectations with services provided, treatments recommended, staff specialty and expected outcome (O’Callaghan et al., 2012). These factors at various points in time either facilitated or impeded the ability of participants with brain injuries to access services. Demonstrating the fluidity and interaction of these factors through time, as illustrated through three qualitative case narratives, is the aim of this article. It discusses implications for clinicians in considering the role that these factors play in access to consumer services, so that clinicians...
might assist in ensuring judicious provision of rehabilitation services to adults following moderate to severe traumatic brain injury (TBI).

**Methods**

This study was conducted with the approval of the Charles Sturt University Ethics in Human Research Committee (protocol: 2007/071), the Royal Melbourne Hospital Human Research Ethics Committee (protocol: 2007/175) and the Alfred Hospitals Research and Ethics Unit (approval number: 170/07). The methodology used in the larger study (O’Callaghan et al., 2009, 2010, 2011, 2012) from which these three case narratives are derived is described, followed by description of the development of the case narratives presented in this paper.

**Qualitative Paradigm**

An interpretivist framework (Denzin & Lincoln, 2005) was used to guide data collection and analysis in this study. Interpretivism is based on the premise that people continually and actively make sense of their life experiences within a cultural framework of socially constructed, negotiated and shared meanings (Hughes, 2003). So, for example, the way that adults with TBI and their significant others interpret their experiences of care following TBI is influenced by negotiated and shared understandings between them and the health professionals that provide their care. These understandings, in turn, have been established in the context of the cultural and societal expectations of service provision following illness. In interpretivism, researchers attempt to interpret why participants act in certain ways, by attempting to see things through their eyes (Grbich, 1999; Schwandt, 2000).

**Data Collection**

A number of different types of interviews can be used in qualitative data collection. The form of interviewing taken in the present research involved an unstructured approach (Minichiello, Madison, Hays, Courtney, & St John, 1999). By taking an unstructured approach, the researchers were able to change and/or adapt questions to meet the varying experiences and impairments (i.e., cognitive–communication) of participants. The interviews in this research were conversations between the first author and the participants, focusing on participants’ perceptions of themselves, their life and experiences throughout the healthcare journey following a TBI.

Participants directed the interviews in this research with only minor input from the researcher. The researcher did have certain questions that formed the basis of a broad interview guide. However, when asking these questions, the researcher followed a conversational style of questioning rather than an interrogative style. The interview guide was developed around a list of topics of interest to the researchers, generated from the preliminary analysis of the questionnaires. The topics of interest were not formulated into fixed questions with specific ordering, but were used to guide the interview and to probe for further information. The use of the interview guide was flexible and open to change throughout the interviewing process.

Before interviewing participants, the first author provided participants with an information sheet and consent form detailing the aims of interviewing, its benefits and risks (such as fatigue and surfacing old emotions), how confidentiality would be assured and the time estimated to be needed to complete the interview. The researchers also travelled to a place of each participant’s choosing (i.e., home or a local café) to conduct the interviews. The time taken to complete interviews varied from 45 minutes to 2½ hours, depending on participants’ levels of engagement and fatigue. Interviews were recorded digitally, with participants’ permission. Interviews were then transcribed for later analysis. Fourteen people with TBI and nine significant others participated in the interviews.

**Data Analysis**

A thematic analysis, within a phenomenological approach, was used to analyse the data from the interviews. According to Morse and Field (1995), phenomenology seeks to understand the lived experiences of individuals and their intentions within their ‘life world’. Within this approach, the researchers asked participants what it was like to access health care following a TBI. Phenomenology was the method of choice for this research as it sought to elicit, understand and make sense of participants’ experiences. There are four main existential premises that guide phenomenological reflection: lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality or communality) (Morse & Field, 1995). An awareness of these four existential premises was important in guiding the researchers’ later analysis of participants’ experiences as revealed in the interview transcripts. One critical aspect of phenomenology is the need for the researchers to suspend their own views or preconceived ideas about a phenomenon and to seek to understand it through the eyes of participants. The aim of this type of inquiry is to show that although the phenomenon under investigation is experienced uniquely by each individual, there exists underlying unifying
meaning of the experience that is essential and invariant for all people (Hickson, 2008).

Procedures for ensuring rigour in qualitative research were followed. For example, the research findings are grounded in the data, with thick description using participant quotes illustrating findings. In addition, participant validation was used to ensure that our interpretations of the data as researchers were consistent with the feelings and experiences of participants with regard to the continuum of care they experienced following their TBI. All interview summaries were returned to the researchers and all participants in this study agreed that the summary was an accurate synopsis of the issues they had spoken about in their interview.

The data generated from the interviews in this study were analysed in two ways. First, traditional thematic analysis involving coding and categorising into higher-order themes was undertaken, and saturation of themes was achieved in the 17 interviews. The five themes arising from this analysis have been reported previously by our group (O’Callaghan et al., 2012). Second, three transcripts illustrating very different healthcare journeys were selected and analysed using narrative analysis approaches (Josselson, 2006; Sandelowski, 1991). In using this approach to data analysis, the richly detailed expositions of the participants’ healthcare journey narratives were retained. These three narratives demonstrate the critical importance of timing in planning for future services after discharge for individuals with brain injury. The three stories selected for presentation in this paper were selected using maximum variation sampling. The three participants selected in this study varied on the basis of their degree of rurality according to the Accessibility Remoteness Index of Australia (i.e., highly accessible, accessible, moderately accessible, remote and very remote) (Commonwealth Department of Health and Aged Care, 2001) as well as on the basis of the level and type of healthcare funding allocated to finance their rehabilitation (i.e., public, private or compensable funding). As a result, the narratives document differing experiences, although with common underlying themes. The narratives presented in this article are made up of participant quotes linked by researcher summaries of what was reported in the interviews. As much as possible, participant quotes are used in order to convey their experiences authentically.

The three participants’ healthcare journeys conveyed in this article are visually represented in a model that maps access to services in comparison to the four phases of rehabilitation recommended in clinical care guidelines (Accident Rehabilitation and Compensation Insurance Corporation & National Health Committee, 1998; British Society of Rehabilitation Medicine & Royal College of Physicians, 2003); that is, acute care, residential rehabilitation, non-residential rehabilitation and longer-term community support.

**Participants**

In the larger study from which the data in this paper are drawn (O’Callaghan et al., 2009, 2010, 2011, 2012), 23 people with brain injury and their significant others were interviewed. This paper presents three narratives from the larger data pool, those of Bettina, Melinda and Oscar. To maintain the anonymity of the participants, all names, rehabilitation hospitals and places of residence are pseudonyms. Brief biographical sketches of the participants are presented here. The three participants had important differences which were initially thought to have affected the services they received (i.e., they lived in different locations and were allocated different funding models to cover the costs associated with their treatment) (see Table 1). They also represent the range of healthcare journeys related by all 23 participants in the larger data set.

**Bettina.** Bettina was born overseas. She moved to Australia with her daughter when she married her first husband more than 30 years ago. This relationship has since broken down. Bettina holds a postgraduate degree in psychology and worked as a lecturer at an institute of higher education before sustaining her TBI 5 years ago. Nine years ago, Bettina’s mother died. Ten weeks after that her daughter, Sharyn, committed suicide. In between her mother and daughter dying, Bettina was hospitalised for neck surgery and suffered a mild stroke. Bettina has a history of depression. Bettina’s current partner, Phillip, has children and grandchildren from a previous marriage, who do not speak to Bettina. Bettina and Phillip are currently self-employed. They work as stall holders selling leatherwork, dolls and collectables, while travelling between local markets. They also conduct paper runs. Bettina lives in an inner regional centre and accessed health services following her TBI as a public patient.

**Melinda.** Melinda emigrated from Eastern Europe when she married her first husband. She had a daughter during this marriage who until recently lived at home with her and her current husband, Drew, and their two other children. Melinda was 37 years old at the time of the interview and is a trained accountant. However, she stopped working following an unsuccessful return-to-work programme implemented 1 year after the TBI. At the
time of her interview Melinda was a stay-at-home mother and housekeeper. Melinda married her second husband, Drew, soon after she sustained her brain injury. Melinda reported that her marriage is strong. She stated she was lucky to have an intelligent husband who was able to support her and her family following her brain injury. Melinda lived in an outer suburb of a metropolitan centre at the time of interview. She accessed mainly public health services following her brain injury. However, she also reported paying privately for specialist brain injury services.

Oscar. Oscar sustained his brain injury after being assaulted following a night out in a metropolitan centre with his friends. Before sustaining his brain injury, Oscar worked as a senior project manager in a national company. He resigned from this role following an unsuccessful return-to-work programme. At the time of his interview, Oscar was employed as a website project officer within a charity organisation. Oscar completed an undergraduate degree in information technology and telecommunications. Oscar has supportive parents. He was 28 years old when he was interviewed. At the time of his interview Oscar lived in a metropolitan centre. He accessed private and public health services following his brain injury. Oscar had private health insurance and received a lump sum payout from the Victims of Crime Tribunal to help fund his care.

Results
The data in this paper are presented as three narratives. An analysis of the variation of person-related factors (i.e., acceptance and readiness, support, advocacy, right service at the right time and mismatched expectations) over time, facilitating and impeding access to the different stages of rehabilitation, is provided in relation to each narrative, and these factors are mapped according to the stages of rehabilitation model presented in Figure 2. In this way the interaction of factors determining access to services across time is demonstrated.

Bettina’s Journey
It was a Saturday night in July, when Bettina leant over her second floor balcony to inspect the curtains her partner Phillip had just hung, when she fell.

I ran straight out, because I was hanging the curtains and Bettina was outside. The next minute I saw her go over the balcony, I went to grab her but missed. I just flew down [the] stairs and virtually saw that she was alive. I got on the phone because the neighbours were home and they’re nurses. (Phillip)

Bettina’s neighbours worked for 40 minutes to resuscitate her while they waited for an ambulance to arrive. Bettina was flown to a metropolitan acute specialist hospital for her acute care. She remained there for approximately 20 days before returning home. Phillip commuted daily from the rural centre where he lived to the metropolitan centre to visit Bettina while she was in hospital. Phillip reported receiving no accommodation or travel support during this time. However, he reported that he needed to return home daily to feed the animals and work.

I’d leave down there after tea, come home, look after our animals, go to bed, get up, do our two mail runs, and then go straight down. It took 3 hours to get there depending on the traffic. (Phillip)

Bettina remembered receiving quit smoking brochures during her acute stay. However, neither Phillip nor Bettina remembered receiving any information regarding her TBI and the symptoms that were to follow.

Probably the only regret or criticism I’ve got of the hospital is that I wish someone had sat down and explained to me the frustration and rage that I would feel. It’s nothing for me to throw half a dozen glasses across the room. (Bettina)
Bettina reported she received mainly surgical care while at the acute metropolitan hospital (i.e., facial surgery to fix bone fractures) and Bettina and Phillip reported receiving little support once Bettina was discharged home.

It was all of a sudden like you’re on your own. Not just on your own but out the back of nowhere. No one cares, you're gone.

(Bettina)

Bettina thought her GP was responsible for managing her care once she was discharged from the acute hospital. However, Bettina reported that her GP’s attitude, competence and poor knowledge of TBI did not help her recovery. ‘The local doctor, he’s bloody hopeless. He won’t listen’ (Phillip). Bettina now avoids going to see her GP.

He’s there for the money. The amount of times Bettina would go, ‘I’ve got to get another prescription, I wonder if he’s away and I can get someone else.’ I keep saying to her, ‘Go to someone else’, but you know there are not many doctors [in the country].

(Phillip)

Bettina reported receiving 3 to 4 months of outpatient services following a referral by social services to a community-based rehabilitation programme for return-to-work services. She stated that this period of rehabilitation was extremely beneficial.

I was eligible for rehab and a girl, Michelle, treated me. She was brilliant because she picked up there was a major problem with my hand. She organised for me to see a surgeon about it. She was really good. She set goals with me.

(Bettina)

Eight months after Bettina’s accident, Phillip and Bettina’s relationship broke down and Phillip left. Phillip reported receiving no formal support services or counselling to help him understand what Bettina was experiencing. He stated that had he received these services, he might have been more supportive.

If they’d have said, ‘look you’re going to have problems’, then we both would have been prepared for it. We wouldn’t have gone off the handle and said, ‘well stuff you’.

(Phillip)

Not long after Phillip left, Bettina met another man who had also sustained a TBI. She reported that the time she spent in this new relationship helped her to gain insight into her own behaviour.

Thirteen months after Phillip had left I started seeing a man who also had a brain injury. I think the funny part about it was, the thing we most had in common is my face. It is constantly numb and it drives me mad. Apparently it’ll always be like that and he knew exactly how that felt because he had the same problem. But he would get into, oh God, his rages were worse than mine. He was drinking a hell of a lot more. That was a pretty big wakeup [call] because I’d sort of look at him and think, ‘is that what I was doing to Phillip?’

(Bettina)

Bettina’s relationship with this second man broke down and in time Bettina and Phillip’s relationship was renewed. When reflecting on the experiences they had following Bettina’s TBI, Phillip reported:

In the hospital, the care couldn’t have been better, but the information that they pass over to you in there and afterwards was just non-existent. Virtually, when Bettina left the hospital, the care was virtually non-existent. But if they had’ve been able to give us a list of services, it may have saved us a lot of drama and hassle and heartache.

(Phillip)
IMPORTANCE OF TIMING WHEN PLANNING SERVICES

**FIGURE 3**

Bettina’s ability to access services. Personal factors: acceptance and readiness (black line), support (dotted line), advocacy (grey line), right service at the right time (lines of dashes) and mismatched expectation (line of squares).

Bettina added to this, saying:

_I’ve probably fallen between the boards, haven’t I? I wasn’t [compensable], I wasn’t [private health], I wasn’t any of those. So I just fell through the gaps. There weren’t dollars there. So I’m cynical, if there’s no dollars, people don’t worry._ (Bettina)

**Interpreting Bettina’s Journey in the Light of the Interaction of Factors**

Figure 3 reflects the impact of the five person-related factors on Bettina’s healthcare journey. As can be seen, only twice were the factors support, the right service at the right time and matched expectations in place to enable Bettina to effectively access services. This occurred first in the acute phase of Bettina’s care, when she was admitted to a specialist acute metropolitan hospital. At this time she had strong support from her partner Phillip who travelled to be with her daily, the service she needed (i.e., acute care) was available and, given how impaired she was, she expected to receive the service and was therefore motivated to accept it.

The second instance in which person-related factors aligned to enable effective access to services was when Bettina received outpatient rehabilitation services. Her access to this service is depicted by person-related factors once again rising above the stages of rehabilitation model, indicating facilitated access. A service was available that met Bettina’s needs and expectations and therefore she accessed it. As can be seen in Figure 3, person-related factors facilitating and impeding Bettina’s access to services were fluid, changing over time.

For example, Bettina’s acceptance of her TBI and readiness to engage with services increased slowly over time. This factor therefore changed from impeding access to facilitating it.

As Bettina related in her narrative, she did not know at the time of her injury that she had sustained anything more than physical injuries. Therefore, she was unable to accept the non-physical consequences of her injury. Bettina did talk, however, about a growing awareness and acceptance of the cognitive sequelae of her TBI (e.g., her uncontrollable rage) when she spent time with another person who also had a TBI. This is depicted in Figure 3, as the personal factor acceptance and readiness slowly rises from impeding to facilitating access to services.

Initially, the factor right service at the right time also played the role of a facilitator (i.e., Bettina received acute care services when she was medically unwell). At this time Bettina and her family expected and advocated (i.e., rang an ambulance) for acute services and they were received. However, once Bettina was discharged from acute care, she was not referred for further services. Nor did she perceive a need for them. Therefore, the factor right service at the right time no longer facilitated her access. Finally, the right service at the right time re-emerged as a facilitator when Bettina was referred to Commonwealth Rehabilitation Service for vocational rehabilitation. At this stage, Bettina felt she needed the service and the service provided at this time met her needs.

Like the factor the right service at the right time, Bettina’s access to support initially acted as a
facilitator but changed to impedance when Phillip and Bettina’s relationship broke down. Phillip reported leaving Bettina as he did not understand her TBI and the cognitive and behavioural sequelae she suffered (i.e., memory lapses, bouts of rage and frustration). He reported that had he been given information about Bettina’s TBI and had support been available to him, he would have been better able to cope when she was discharged home.

Taking into account that Phillip and Bettina’s relationship broke down and that she was unaware she had a TBI, it is little surprise that the factor advocacy did not ever facilitate Bettina’s access to services. A small rise in advocacy efforts is noted in Figure 3 when Bettina approached her GP to request access to counselling services. However, this attempt to self-advocate in order to obtain services was not successful and was not repeated.

From Bettina’s story, it is evident that the services she received following her TBI were affected by the degree of her acceptance of her TBI and therefore her readiness to engage in therapy, the support she received, and her ability to access the right service, which matched her expectations, at the right time. Given Bettina’s poor level of awareness of her TBI, the lack of information she received and her limited access to advocacy, it is not surprising that she accessed only acute care and time-limited outpatient services.

**Melinda’s Journey**

Melinda sustained her head injury one morning after collapsing in her daughter’s room at home. Her partner, Drew, found her and immediately rang an ambulance.

*It happened on the 26th of July at seven o’clock in the morning. I don’t remember anything. I remember the night before. I had a huge argument with my ex-husband and I went to bed crying, that was the way I fell asleep. I woke up in the hospital 2 weeks later.*

Melinda was taken from her home to the closest regional hospital via ambulance. At this hospital, Melinda reported that her husband had to strongly advocate for her to be seen by a doctor. Melinda reported that she felt she would have died at the hospital.

*My husband was especially Forceful with doctors. He told them, ‘Look, she was pulling her hair out when she fainted. She’s got something wrong with her head.’ They were keeping me in intensive care in the emergency department waiting for a doctor to come and see me. They had no idea what was wrong with me. They didn’t even go and find out. So my body started to shut down bit by bit. By that time my husband just pulled them and shook them up, ‘Hey, she is dying.’ So I could have died if my husband didn’t push the staff hard enough, I would have died in [name of the regional] hospital.*

Melinda was airlifted to a metropolitan specialist acute hospital following a magnetic resonance imaging (MRI) scan at the regional hospital which revealed blood clots in her brain. She stayed at the metropolitan hospital for approximately 3 weeks. During this time, she had neurosurgery and spent a period of time in a coma.

*I don’t remember the time I was recovering in the coma. My family said it was a huge shock for them to see me acting like a little girl. I started withdrawing. I did not recognise them. I did not recognise my children. They were very hurt. The biggest mistake was that nobody could explain to the children why mummy was like that.*

Melinda reported she received medical, allied health and psychology services while at the metropolitan specialist acute hospital. She stated she was happy with the medical care she received while she was there, but one big issue she identified was the lack of information given to her by some medical staff.

One day, I said to one of the surgeons, ‘Who did the surgery?’ I wanted to speak with one of them. I wanted information. I wanted explanation. I felt like I was dying. I needed somebody to tell me what had happened to me. I went to the bathroom, there was no mirror, I couldn’t see myself. I put my hands on my head and I was half shaved. I could feel the stitches and I thought, ‘What has happened to me?’ I had no proper explanation of what had happened to me. I didn’t know why I was there. What had happened? Who brought me there? I needed an explanation.

Melinda was transferred from the metropolitan specialist acute hospital to a metropolitan public medical centre for inpatient rehabilitation. I escaped rehab on the 19th of August. I was in rehabilitation for 3 days. Melinda reported staying in residential rehabilitation for 3 days before discharging herself. Melinda reported that she was never told the reasons why she needed to receive rehabilitation and as she was placed in a ward with people she perceived to have intellectual impairments, she felt she did not belong.

*If they explained to me the real purpose of rehabilitation and didn’t treat me like a mental person, I would have stayed longer. I told the doctor on Sunday night, I told him, ‘If you don’t discharge me and let me go home to rest properly, then I will leave. I’ve got a family who can take me to the rehab to be treated or trained.’ I remember on the Sunday I left. My husband came in and I said, ‘You take me home*
Melinda reported that she received limited allied health services while in residential rehabilitation. However, she qualified this saying that she did not have insight into her difficulties at that point, so she did not understand or comply with needed therapy.

I had a physiotherapist who was trying to teach me to walk straight and I remember I was very disappointed. At that time I was freshly hurt and not accepting what had happened to me. They asked me, I’ll never forget, I had a huge white line in front of me and the physio asked me, ‘Can you walk this white line?’ and I said to him, ‘What do you think, I’m a drunk person, I can’t walk straight?’ He said, ‘No, just for your balance.’

Melinda saw that while she was in residential rehabilitation she felt she needed to rest in order to recover. She felt that she was unable to do that in a busy, noisy hospital; therefore she left. Once Melinda discharged herself from rehabilitation, she and her husband went away for 4 days. During this time, Melinda stated she slept constantly. Melinda reported that her husband kept in contact with the rehabilitation hospital at that time so that they could continue to monitor her recovery.

My husband had to give up his work to look after me. I had to stay with my brother and my sister-in-law for one month after rehab. My sister-in-law stayed with me constantly. She looked after me and bathed me. I could dress properly. But there always had to be somebody there to hold my hand and talk to me.

After a period of time, Melinda started to access public health services as an outpatient. However, she reported that the staff employed within this service were not specialists in brain injury. Therefore, the therapy she received there was not always helpful.

They put me in a public rehab stream which was very cheap. Not just cheap but not well-trained people. The staff weren’t trained how to help people recovering from brain surgery. They had no idea. I was speaking with them. I was trying to find out what their expectation was. ‘Am I okay? Is it alright to be like that?’ They replied ‘I’m sorry we can’t help you with that, you have to go back to the [name of specialist acute metropolitan hospital].’ But I can’t go there without a referral so I had to go back to my general practitioner, tell the story to him and then he told me that I had to organise that myself. So they were of no help.

Melinda reported that she constantly had to push her general practitioner for referrals to access counselling services, to have repeat MRI scans and to access follow-up neurosurgery reviews, all of which she had to self-fund.

I didn’t have private insurance but I paid privately. I paid the full charge for the MRI tests. I paid the full charge for the brain surgeon. I paid full price for a psychologist to see me.

Melinda also reported that little support or information about her brain injury was provided to her husband and children.

Luckily, I’ve got an intelligent husband. He dealt with my brain injury. But he also had to work because I couldn’t work. He had to work to support us so it was very hard.

Melinda reported that her family received no form of accommodation or travel subsidy throughout her healthcare journey. She stated that she did not even know support was available.

**Interpreting Melinda’s Journey in the Light of the Interaction of Factors**

Figure 4 illustrates the impact of the five personal factors on Melinda’s healthcare journey following her brain injury. As can be seen, services were available and family support remained constant throughout the entirety of Melinda’s healthcare journey. Specialist services were provided by the metropolitan specialist acute hospital and residential rehabilitation was then available through a public medical centre. Non-residential, outpatient services were then provided by Melinda’s local public health centre, and ongoing monitoring was available through yearly outpatient neurosurgery reviews at her metropolitan specialist acute hospital.

Melinda reported varied access to services due to reported problems with lack of insight delaying her readiness for services. Melinda reported she was not ready for services until after she had returned home and developed an understanding of what had happened to her. This was the reason Melinda gave when explaining why she needed to leave inpatient rehabilitation.

I didn’t know what had happened to me. One day I was perfect, the next day I was a half vegetable. I needed to go home, to see that everything was okay. Then I would be right to go back to rehab. I needed to understand what happened to me. Then I was ready to go back and get better.

Mismatched expectations also resulted in disrupted continuity between stages in Melinda’s healthcare journey. She expected that the rehabilitation services provided to her would be specialist. In reality, this was not the case. Mismatched
Melinda’s ability to access services. Personal factors: acceptance and readiness (black line), support (dotted line), advocacy (grey line), right service at the right time (lines of dashes) and mismatched expectation (line of squares).

expectations were evident in her annoyance with the outpatient services provided to her by the local public health centre, which she described as *cheap with not well-trained people*. At this time Melinda had accepted her injury, was ready for services and had strong family support. This meant that the facilitators (i.e., acceptance and readiness, and support) outweighed the impediments (mismatched expectations) and thus Melinda continued to access the service even though it did not meet her expectations.

Melinda’s story shows the dynamic and complex relationship between person-related factors which appear to play a role in determining consumers’ access to services regardless of service availability following brain injury.

**Oscar’s Journey**

Like Melinda, Oscar had services continually available to him. He also had constant support from his family and continuing advocacy from his family and staff involved in his care. His journey is as follows.

Oscar sustained his brain injury after being assaulted when out late with friends in the city.

It was around about 4.00 a.m. Some people saw me on the sidewalk bleeding badly from the face and initially they thought I was just drunk but then upon inspection, they found out no, I had been assaulted. So an ambulance was called and I was taken to the [name of metropolitan specialist acute hospital]. I obviously don’t know all the details. I just remem-

her waking up. The doctors said that 95% of people would have died as a result of the injuries that I sustained. Your body goes into flight or fight mode, and fortunately my body went into fight mode.

Oscar was initially treated on the scene by paramedic staff before being transferred to a metropolitan specialist trauma centre for his acute care. Oscar reported he could not remember much of his time in the acute hospital. He remembered receiving adequate medical care and he mentioned he had two friends who were ICU doctors, who were able to look out for him and see that he got the care he needed.

I come from a reasonably privileged background and one of my best friends’ brother is a doctor at the [name of metropolitan specialist acute hospital] in intensive care unit and his fiancée works in intensive care. Because I have friends in the medical profession, they’re going to ask for updates and check how I’m going.

Oscar reported staying in acute care for somewhere between 4 and 7 days before being transferred to a metropolitan private hospital for specialist neuro-rehabilitative care. Oscar remained at this hospital for approximately 4 weeks before self-discharging.

My frustration grew over time because I didn’t want to be there. I wanted to be doing my job, living at home, doing my own thing. I was in a situation where my career was going very, very well and all of that independence had been stripped away. Being locked down in the room, in the ward and having an
orderly follow me around for up to a month because I couldn’t pass the post-traumatic amnesia memory test was extremely frustrating.

Oscar reported he self-discharged because at that time he was fed up with the hospital and perfectly capable of looking after himself. Oscar remembered receiving allied health services while in rehabilitation, including physiotherapy, speech therapy, social work and one consultation with an occupational therapist.

Physio, I had to have numerous times a week. Once again, it was very frustrating. Having been a regular gym attendee, I liked running on the treadmill, doing you know an average of 12 km per hour. But I was told I’m only allowed to do 5 km per hour and walk. Also, being very coordinated, having been a windsurfer and having state titles to my name and losing my balancing skills was pretty hard. But I’m pretty persistent so I just stick at it until I get on top again.

Oscar also reported that he received neuropsychology services and adequate medical care.

I did a lot of neuropsychology and my building a rapport with my neuropsychologist was key. I had faith in her and I trusted her and that was a key factor I knew that I could fall back on that.

Once discharged, Oscar returned to his parents’ home for a period of time before returning to his flat. Oscar reported this was a difficult time for him as he once again felt as if he had lost his independence.

I had to move back in with my parents. There were a couple of issues there in that as I was a victim of crime. I’d been assaulted. I was pretty nervous about going back to my apartment, and not being able to drive as well, was a big factor. So yeah, that independence was all stripped away.

Oscar received outpatient services through a public medical centre. The services he received included case management, return-to-work services, a driving assessment, ongoing allied health services including physiotherapy and neuropsychology, and ongoing specialist medical care. Oscar reported that the length, intensity and duration of these services varied throughout his recovery, according to his need. Oscar stated that his original return to work plan was unsuccessful.

I wanted to go back to work and they wouldn’t let me back to work for 3 months. I think my first week back was a 6 hour week, doing 2 or 3 hours a day. I was in a national role at the time as a project manager with a high level of degree and responsibility, so you can imagine that I couldn’t fulfill my duties. Eventually I had to resign but with the support of my managers and the organisation, I was liaising with senior management there and they were very supportive. But being highly successful in business and being 25 at the time, and having to resign I guess led to post-traumatic depression because in my situation, my job was a very large part of my identity.

Oscar reported he no longer received regular services or ongoing monitoring. However, he stated that he has built a relationship with all of his therapists and therefore believed it would not be hard to re-engage with services if needed.

I usually find a way of getting around the system. Which is probably cocky and arrogant but I’m able to do that . . . I have always had somebody to fall back on but that’s because of the relationships that I’ve made with those people, not because the processes exist. I often get my way, but that’s through a lot of persistence and a lot of battling red tape and administration.

Oscar received compensation through a lump sum payout through the Victims of Crime Tribunal. Oscar believes this lump sum does not reflect his loss of earnings nor ongoing medical costs.

I had lost well over $100,000, in earnings. I got awarded the maximum amount which was only around $20,000 so I lost a heap of earnings. I got the maximum lump sum possible and it didn’t even cover anything and certainly no emotional compensation or punitive compensation of any sort.

Oscar believes that general funding for head injuries is inequitable.

Perhaps with the Victims of Crime money may have covered the hospital charges and I know the compensate people, which most of the people were, would have been awarded ten times the amount that I got from Victims of Crime. So it’s quite inequitable.

Apart from funding impacting on Oscar’s continuum of care, Oscar also reported:

Had my parents not been there, I would have been a lot worse off. I mean I had my room at my house and they fed me, etc. If I hadn’t had that I don’t know how I would have recovered. Well, it certainly would have been harder.

Interpreting Oscar’s Journey in the Light of the Interaction of Factors

Figure 5 reflects the impact of the five personal factors on Oscar’s healthcare journey. As can be seen in this figure, the factors support, advocacy and the right service at the right time, remained constant through Oscar’s continuum of care. The factors that changed, resulting in varied care, were
Oscar’s insight affecting his acceptance and readiness for services, and his expectations compared to those of his service providers about the characteristics of services provided.

The black line depicted in Figure 5 reflects how Oscar's level of acceptance and readiness changed through time. Oscar reported that he did not develop a proper understanding of his brain injury and his changed capacity until after he left residential rehabilitation. Therefore, his willingness to truly engage with services, depicted by the raised black line, was not evident until he began to access non-residential outpatient services.

Given Oscar’s limited acceptance of his injuries in the acute and residential rehabilitation stages of his care, it is not surprising that his expectations for service (as depicted by the line of squares in Figure 5) was mismatched with the expectations of those providing his service. This mismatch in expectations, alongside Oscar’s impaired insight, meant that Oscar engaged in a period of false compliance with therapy while in inpatient rehabilitation before he eventually abandoned the service.

Regardless of this fact, the constant support and advocacy from Oscar’s family (see the dotted and grey lines in Figure 5) meant that even though he disengaged from care in a residential setting, they were able to advocate for community-based brain injury services following his discharge. Thus, even though Oscar needed time to accept his brain injury and become ready to access services, he still received continued care in line with clinical care guidelines.

Discussion

Previous articles presenting aspects of this research (O’Callaghan et al., 2012) provided a sequential discussion of each personal factor impacting upon access to services following brain injury. These factors included degree of acceptance of impairments and readiness to engage with therapy of an adult with brain injury, their ability to access support, the presence of an advocate, whether the right service was accessed at the right time and whether the services accessed matched the expectations of the person accessing them. This article adds to understanding of the influence of these factors on rehabilitation for participants with brain injury, by reflecting on how the factors change through time, acting as either a facilitator or impediment when adults with brain injury attempt to access services.

The central concept in the data discussed in this article is the element of time, and how, as a result of personal factors changing through time, access to services can change. In the case of an adult with brain injury, stakeholders (i.e., healthcare provider or consumer, participant with brain injury or significant other) often have varying views on the importance of time and its applicability to services accessed. For example, healthcare providers often reflect on time as an important indicator for client outcome. Time post-injury has long been viewed by clinicians as a prognostic indicator of severity of injury. Katz and Alexander’s (1994) study of outcomes based on length of coma for 199 people with brain injury indicated that outcomes were progressively worse as the duration of an adult’s coma
increased. Time post-injury can also be viewed as an indicator for potential recovery. Mackay, Bernstein, Chapman, Morgan, and Milazzo (1992) argued that the earlier an adult accesses rehabilitation following brain injury, the greater the potential recovery.

Clinical care guidelines stipulate that timing is important to ensure a person’s ultimate recovery following brain injury. They state that rehabilitation should start as soon as possible and continue for as long as necessary (British Society of Rehabilitation Medicine & Royal College of Physicians, 2003; New Zealand Guidelines Group, 2006). Early rehabilitation following brain injury and re-admission to rehabilitation have been shown to be beneficial for physical improvement and return of self-care skills (Tuel, Presty, Myethaler, Heinemann, & Katz, 1992), for preventing secondary complications and for facilitating overall recovery (Mackay et al., 1992). Gentleman (2001) stated that recovery following brain injury is greatest in the first 3 months following injury. Therefore, clinicians see an obvious advantage in working with adults with brain injury during this period, rather than trying to ‘catch up’ later.

Nevertheless, as highlighted by participants’ accounts in this study, consideration of the theoretical recovery curve following brain injury (Gentleman, 2001) and a wish to maximise a person’s recovery during periods of increased neuroplasticity should not be the only considerations clinicians reflect upon when deciding when clients should receive services. The data reported in this study show that personal factors that involve the consideration of time, such as consumers’ degree of acceptance or awareness of their brain injury and readiness to engage in therapy, are also important.

According to Morton and Barker (2010), deficits in self-awareness and denial of acquired impairments can seriously interfere with participation in rehabilitation by adults with brain injury. Deficits in self-awareness have been reported to cause problems with engagement in therapy tasks, compliance with suggested behavioural changes, and uptake and use of compensatory strategies. Adults with impaired awareness are often poorly motivated to comply with therapies to address deficits that they do not recognise or believe exist (Sherer et al., 1998). Therefore, regardless of clinicians’ wishes to maximise client gains during periods of increased neuroplasticity, people with brain injury may not be cognitively ready to engage with therapy during such periods.

The level of self-awareness in people with brain injury improves over time following brain injury (Fleming, Strong, & Ashton, 1998). If lack of awareness of deficits persists despite interventions designed to facilitate its development (e.g., video feedback, education regarding deficits, reality testing through engagement in real-life activities), it may be necessary to cease formal rehabilitation, with appropriate supports in place for a period of time, to avoid client frustrations with the rehabilitation process (Schmidt, Fleming, Ownsworth, Lannin, & Khan, 2012). If formal rehabilitation was to be ceased long term, monitoring would be essential to determine whether self-awareness developed at a later stage, and whether intervention was appropriate at this time.

The degree of self-awareness is one example of a personal factor which impacts upon the ability of an adult with brain injury to engage in therapy. This factor can impact negatively on a person’s motivation to engage with therapy, affecting their likely outcome, regardless of health professionals’ desires to provide early rehabilitation as defined by best practice guidelines. Acceptance and readiness, along with the other person-related factors, support, advocacy, the right service at the right time and mismatched expectations, must be considered if available services are to be accessed. Without consideration of these factors, services allocated may not be utilised. For people with brain injury and their families to be actively engaged in a service, they first need to acknowledge their need for this service. Unless the person with brain injury can identify that he or she has a brain injury with secondary impairments that require therapy for improvement, further therapy may be futile. The person may not yet be ready to accept their impairments and is therefore not ready for treatment. Therefore, service referrals generated at this time may not be engaged with.

In service allocation, clinicians’ consideration of the degree of support or advocacy available to clients with brain injury and their families is also important. Formal services can, at times, disempower clients and their families (Foster et al., 2012; MacPhail, 1998; Stringer, 1999). Limited historical involvement in therapy goal setting and continuum of care planning can mean that adults with brain injury become passive recipients of health services. Without a strong advocate or support person these clients may become ‘lost in the system’. Clinicians need to monitor closely clients with poor support networks and limited advocacy skills following their discharge from formal services, to assist them to access services when needed. If the provision of client monitoring following discharge is not within the scope of the service provided, clinicians need to refer these at-risk clients to formal case management services.

When planning future services, clinicians also need to openly discuss with people with brain injury their degree of self-awareness and motivation to engage in therapy. Participation in real-life activities is designed to increase self-awareness and motivation to engage in therapy, and provide a basis for planning services. The importance of timing when planning services needs to be considered in enacting this approach.
injury and their families what their needs and expectations are of the services to be provided. In this way services that clients are referred to are more likely to match their expectations and to be provided at a time when they are needed or wanted. Only after joint consideration of non-personal and person-related factors will appropriate service referrals be generated with a greater likelihood of services being truly engaged with.

Although the five person-related factors discussed in this paper were identified following the analysis of 386 surveys and 17 in-depth interviews, only three participant narratives were reviewed in this paper. Further exploration of the impact of these five factors on a greater number of health narratives from adults with brain injury would help to strengthen the transferability of interpretations made in this paper to other adults with TBI and their families, and to other healthcare contexts (e.g., in different countries with different healthcare funding models).

This paper is the first in the TBI literature to discuss explicitly the need for and barriers to health services experienced by consumers with brain injury, and how these factors change throughout time, either impeding or facilitating access to health care. As stated in the introduction to this article, national and international clinical care guidelines exist recommending a continuum of care that is widely recognised as best practice for intervention following TBI. However, the intervention received may not be what is wanted, needed and useful for people with TBI and their families at a particular point in time. Service providers and guideline formulators should be open to the possibility that, if recommendations for intervention are not useful for certain clients with TBI, then service provision needs to be adapted, regardless of the time pressures imposed by service policy and attempts to maximise client gains during periods of greatest neuroplasticity. The narratives presented in this paper illustrate that a ‘one size fits all’ approach is not what adults with TBI and their families want or need. The person-related factors of individual adults with TBI and their significant others should be continually reviewed and considered, in addition to pressures related to the context of care (e.g., policy and resource allocation) and health professionals’ perceptions of client characteristics (i.e., clinical and non-clinical characteristics), before referrals for services are made. Only when a match exists between the characteristics of services provided and the beliefs and expectations of the adults with TBI and their families, will available services be utilised effectively and equity in TBI care achieved.

References


