Perceptions of Long-term Community-based Support Following Severe Acquired Brain Injury

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Many individuals require long-term community-based support following acquired brain injury (ABI). However, very few studies have examined individuals' perceptions of these support needs. The present exploratory study examined individuals' perceptions of community-based support following severe ABI. Participants included eight individuals (aged 20–48 years) with severe ABI, seven relatives and three case managers. The individuals were receiving long-term specialised lifestyle support ranging from 3–70 hours per week. A structured interview with open and closed questions was developed to explore perceptions of individuals' support needs across the areas of personal and home-based activities, community-based activities, self-organisation and vocational activities and social and psychological well-being. The questions investigated whether support was needed, the importance of support, the sources of support, the effectiveness of support and the need for change. A comparison of the three respondent groups' perceptions of support indicated a general consensus that community-based activities were the most important and most effective area of support. When the issues raised by the three respondent groups were compared and contrasted two main themes emerged from the data, which were labelled "relationships" and "individual choice versus support needs". These themes are discussed in relation to the provision of long-term community-based support services following ABI.

Long-term outcome studies have highlighted that the psychosocial consequences of severe acquired brain injury include social isolation, depression and suicidal behaviour, substance abuse, behavioural impairment, poor vocational adjustment and loss of independent living skills (Morton & Wehman, 1995; Tate, Lulham, Broe, Strettle & Pfaff, 1989; Thomsen, 1984). As most individuals are aged less than 25 years when they sustain their injury, many will require support for 50 years or longer. After discharge from hospital, individuals are often involved in various community-based services, which are generally transitional in nature and focus upon the attainment of specific goals such as independent living or return to work. Although transitional services fulfil the needs of many individuals with ABI, a significant

number of individuals require ongoing or lifetime assistance, particularly during periods of crisis or life adjustment (Willer & Corrigan, 1994). Long-term community-based support services are critical to support family or unpaid carers who are often experiencing the physical and emotional strain of caring. Although carers' perceptions of their support needs have been examined (Harris, Godfrey, Partridge, & Knight, 2001; Webster, Daisley & King, 1999), individuals' perception of their own support needs has generally received less attention in the literature. The following literature review summarises research which has examined individuals' perceptions of support and emphasises the importance of further research in this area.

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Despite the recognition that many individuals require long-term community-based support, research indicates that specialised rehabilitation services are concentrated in the post-acute phase with inadequate long-term specialist services to assist individuals with community reintegration and overall psychosocial adjustment (Fleming, Strong, Ashton, & Hassell, 1997; Willer & Corrigan, 1994). Generic health services are often ill equipped to meet the challenging needs of individuals with ABI or, alternatively, exclude these individuals from assistance on the basis of their diagnosis (Hearn, 2000; McAllister, 1997). In Queensland, there are very few services that specialise in providing long-term community-based support to people with severe ABI (Cameron, Pirozzo & Tooth, 2001). The Acquired Brain Injury Client Integration Service (ABICIS), based in Brisbane, specialises in providing long-term community-based support to individuals with ABI. ABICIS provides long-term support to 20 individuals with ABI on a fee-for-service basis. Many of the individuals supported by ABICIS have a co-morbid psychiatric diagnosis and represent a particularly challenging group of clients to support. Such individuals face a range of ongoing stressors and critical events (e.g., eviction from a residence and conflict with family members). ABICIS has been providing a service for approximately three years that is based on the model of doing "whatever it takes" to assist a person with a disability to achieve "maximum self-determination" within the community in which they wish to live (Willer & Corrigan, 1994). Individuals have a case manager and support workers based in the community to support their needs in diverse areas of daily living. The level of support provided by ABICIS ranges from minimal contact to 24-hour support and supervision.

A review of the literature suggested that, in general, research has used functional measures to determine outcomes following community-based rehabilitation. Although such measures provide valuable information regarding individuals' level of recovery and adjustment, such measures do not reflect the individuals' perceptions of support or whether they believe their support needs are being met. However, there are two studies that described the development of tools for assessing individuals' perceptions of the quality of services. Seibert et al. (2002) developed a questionnaire that explored the perspectives of individuals and families regarding their satisfaction with treatment decisions relevant to the individuals' quality of life. Swaine, Dutil, Demers and Gervais (2003) developed a

standardised questionnaire to evaluate individuals' perceptions of the quality of transitional head injury rehabilitation services. Swaine et al. highlighted that there is often a disparity between what individuals and their families perceive that they need and the services they actually receive. It appears that the latter tool is undergoing further development and is to be used primarily with individuals, just prior to hospital or rehabilitation discharge or within several months post-discharge.

The research conducted by Seibert et al. (2002) and Swaine et al. (2003) highlighted the importance of examining individuals' perceptions of services received during hospitalisation and shortly after discharge from post-acute rehabilitation. However, a review of the literature indicated that researchers are yet to examine the perceptions of support of individuals receiving long-term community-based support. An approach that is often used to gain information regarding the perceptions of individuals with long-term ABI involves qualitative research. Krefting's (1989) early work on community reintegration after head injury is a well-recognised example of this approach. A number of researchers have used qualitative research to investigate phenomena from the perspectives of individuals with ABI. A review of the literature indicated that previous qualitative studies have examined individuals' perspectives on self-identity and personhood (Krefting, 1989, Nochi, 1998), social and community integration (Crisp, 1994; McColl et al., 1998), transitions to independent living (McColl et al., 1999), coping strategies and stresses (Karlovitz & McColl, 1999), awareness of deficits and compensatory strategies (Dirette, 2002) and perceptions of peer support (Hibbard et al., 2002). Two studies that are particularly relevant to individuals' perceptions of support were conducted by McColl et al. (1998) and Hibbard et al. (2002).

McColl et al. (1998) investigated how 18 individuals with moderate to severe ABI defined community integration. They found that the individuals' definition of community integration consisted broadly of four factors, which included general integration, social support, independent living and occupation. Within these factors, nine indicators of community integration were found. These included orientation, acceptance, conformity, close and diffuse relationships, living situation, independence and productivity. McColl et al. (1998) proposed a consumer-driven model of community integration as essential for identifying people's level of integration into their community and those factors that would enhance their community integration.

Hibbard et al. (2002) explored individuals' perceptions of support in evaluating the impact of a community-based peer support programme for 20 individuals with brain injury and nine family members. The analysis found that participants perceived the peer program to have increased their knowledge of brain injury, enhanced their overall quality of life and improved their ability to cope with depression. Minimal benefits were reported in terms of improving social support, coping with other emotions and achieving a sense of control over life. However, the program provided individuals with a sense of "shared experience" and lessened the experience of "feeling alone". Hibbard et al. (2002) also found that individuals' expectations of the program varied from the support they received, with individuals identifying various suggestions for improving the program. The research conducted by McColl et al. (1998) and Hibbard et al. (2002), which used qualitative interviewing approaches, highlighted the need to examine whether individuals perceive that their support needs are being met, although neither study focused upon long-term community-based support.

The purpose of the present study was to examine the perceptions of support of individuals with severe ABI who receive community-based support, as well as the perceptions of family members and case managers. Due to the limited understanding of individuals' perceptions of their long-term support needs, the present study used exploratory methods. A structured interview format with open and closed questions and prompts was developed to examine perceptions of support in preference to designing a specific questionnaire. It was anticipated that the results of this study would provide greater understanding of long-term support needs following ABI and issues associated with the provision of community-based support. The participants in the present study included clients supported by ABICIS, their relatives and case managers. The main research question was: "What do individuals with severe ABI perceive their support needs to be?" In addressing this question an emphasis was placed upon the perceived sources of support, the importance and effectiveness of that support and any perceived need for change. Additional research questions were: "Are individuals' perceptions of support consistent with their relatives and case managers? And, if not, in what ways do they differ?"

Method

Research Design

A mixed methodology approach (Patton, 2002) was used in the present study, in which qualitative

and quantitative data were combined to gain greater understanding of perceptions of current support needs. A structured interview with open and closed questions and prompts was developed from knowledge of relevant literature and from the researchers' experiences in service provision. The interview was divided into two sections, these being perception of support needs and perception of life events, with data from the first section only being reported in the present study. Three strategies were used to facilitate rigour in data collection and data analysis and included triangulation of data sources (Patton, 2002), participant checks (Frankel, 1999) and consensus coding (Rice & Ezzy, 1999).

Participants

The three participant groups in the present study were individuals with a severe ABI supported by ABICIS, their relatives and case managers. Prior to commencement of the study, ethical clearance was obtained from the relevant University of Queensland ethics committee and the executive committee of the Brain Injury Association of Queensland. All participation in the project was voluntary and involved informed consent. Confidentiality for all participants has been maintained. Individuals were excluded from the study if they were less than 18 years of age or their communication skills would have precluded them from participating in the research interview ($n = 2$).

Stratified purposeful sampling (Patton, 2002) was used to identify participants who represented a diverse range of characteristics that might impact upon perceptions of support. These characteristics included age, gender, level of weekly support provided by ABICIS and the absence or presence of a co-morbid psychiatric diagnosis. In order to select potential participants for the study, a matrix of these characteristics was developed and the range for each characteristic was identified for the larger ABICIS group ($n = 18$). As support was the focus of the study, level of support was the first criterion used to generate diversity of the sample. The existing levels of support within ABICIS were initially identified, from which four main categories of level of support were developed as follows: 0–7 hours per week, 8–15 hours per week, 15–20 hours per week and greater than 20 hours per week or daily visits. The second criterion used to determine diversity of the sample was the presence or absence of a co-morbid psychiatric diagnosis, as determined by the treating practitioner. Diagnostic categories

included Mood Disorder, Personality Disorder and Substance-related Disorder.

Therefore, the potential sample comprised two individuals in each level of support category, one with a co-morbid psychiatric diagnosis and one without a diagnosis. Where possible, an appropriate diversity of age and gender were included. Using this sampling method, eight indi-

viduals were invited to participate in face-to-face interviews and all eight volunteered for the study. The demographic and background information for the current sample ($n = 8$) and the other ABICIS clients ($n = 10$) is summarised in Table 1. Table 1 also provides some descriptive data regarding the psychosocial functioning of participants in the sample using the Sydney

TABLE 1
Summary of Demographic and Background Information for the Current Sample of ABICIS Clients and Other ABICIS Clients

Demographic and background information for ABICIS clients	Current sample ($n = 8$)	Other ABICIS clients ($n = 10$)
Gender	6 males 2 females	7 males 3 females
Age: mean (range)	32.9 years (20–48)	34.2 years (20–56)
Time since injury: mean (range)	11.37 years (2–19)	13.7 years (3–40)
Cause of injury		
Traffic accidents	6	6
Falls	1	2
Assaults	1	1
Hypoxic injury	—	1
Severity of injury ('severe' indicated by a PTA duration of 24 hours or greater, or GCS score of 8 or less)	All severe brain injuries	All severe brain injuries
Level of weekly support: range	3 hours (one visit) — 70 hours (twice daily visits) per week	3 hours (one visit) — 49 hours (daily visits) per week
Type of accommodation		
Lives alone	5	7
Lives with a relative	2	2
Lives in a residential care facility/hostel	1	1
Co-morbid diagnostic information*		
Co-morbid psychiatric diagnosis	4	6
No co-morbid diagnosis	4	6
Mobility		
Walks without assistance	5	5
Uses a wheelchair or walking aid	3	5
Transport		
Able to drive	0	1
Independent with public transport	4	4
Unable to drive or use public transport	4	5
Requires support with personal care		
Yes	2	3
No	6	7
Communication impairment		
Yes	4	3
No	4	7
SPRS domains (mean, <i>SD</i>)		
Occupational Activities	6.92 (5.67)	N/A
Interpersonal Relationships	11.90 (3.51)	N/A
Independent Living Skills	14.88 (4.06)	N/A

Note: PTA = Post-traumatic amnesia; GCS = Glasgow Coma Scale; SPRS = Sydney Psychosocial Reintegration Scale;
* the diagnoses were made by a treating practitioner and included the diagnostic categories of one or more of the following: Mood Disorder, Personality Disorder and Substance-related Disorder.

Psychosocial Reintegration Scale (SPRS; Tate, Hodgkinson, Veerabangsa, & Maggiotto, 1999). Case managers completed Version B of the SPRS to reflect the individual's current level of psychosocial functioning (Tate, Pfaff, Veerabangsa, & Hodgkinson, 2004). The three functional domains of the SPRS are each scored out of 24 (a score of 24 reflects maximum functioning). As shown in Table 1, individuals' functioning in the area of occupational activities was rated at a lower level than their interpersonal relationships and independent living skills.

The 8 individuals with ABI were asked to select 1 relative who was invited to participate in the study. Only 1 relative selected declined to take part in the research, as she had not been in close contact with the individual for several months. Therefore, the second group of participants comprised 7 relatives who were aged between 40–72 years of age and included 6 mothers and 1 uncle. The third group of participants included the 3 case managers (2 females and 1 male) who supported the 8 individuals and had worked for ABICIS for longer than 2 years. The case managers all had formal qualifications in the social work and disability field.

Procedures

The 3 case managers assisted with contacting the individuals and their relatives. After participants expressed an interest in taking part in the study, the research assistant met with individual participants at the ABICIS office to explain the project and obtain informed consent. The case managers confirmed that the relatives identified by the individuals had the most regular contact with the individuals and their case managers.

A pilot interview was conducted with 1 individual who had a communication impairment, to provide some indication of the feasibility of the interview for this sample. Specifically, this interview examined whether or not the meaning of the questions were clear, the prompts were effective in eliciting the information sought and the length of the interview was appropriate (Paterson & Scott-Findlay, 2002). This assessment indicated that the questions in the interview were adequately understood. Data for the study was mainly collected through 23 interviews conducted in a private meeting room at the ABICIS office, with case managers providing a separate interview for each of their respective clients. However, due to work, care commitments or geographical distance, it was more practical to conduct telephone interviews with relatives. The research assistant conducted all the interviews with the individuals and

relatives and the primary investigator conducted all the interviews with the case managers. The interviewers met regularly to discuss the interview process to enhance the consistency of data collection. The format of the interview for individuals is presented in Figure 1.

The need to examine coping in the context of multiple daily problems or stressors, rather than focusing on the disability itself, has been emphasised in the literature (Kendall, Shum, Lack, Bull, & Fee, 2001). Therefore, standard prompts for support needs were developed with the assistance of the case managers. The general categories of support needs included personal and home-based activities, community-based activities, self-organisation and vocational activities and social and psychological well-being. The specific prompts for each general category are listed in Table 2 (see Results section). The interview was designed to investigate areas of support that the respondent (i.e., the individual, relative or case manager) perceived were relevant for the individual. Therefore, if the respondent did not identify that the individual needed help in a specific area (e.g., getting dressed), subsequent prompts were not given and the interviewer proceeded to the next area of daily living. Although this prevented an exploration of whether individuals were receiving support that they, their relative or case manager perceived was not needed, this process ensured that the emphasis of the interview was on exploring perceived support needs.

The interviews were audio taped and then transcribed verbatim. Participant checks of interview transcripts were conducted for each individual, relative and case manager within a 1–2 month period from the original interview. The checks with the individuals and case managers were conducted face-to-face while the checks with relatives were conducted on the telephone. The participant checks were conducted to determine the accuracy of the written transcript in relation to the interview. Participants were encouraged to clarify responses and add in any relevant new information. Any changes identified by a participant were directly incorporated into the data. However, individuals requested very few changes to the data, which may suggest a general stability of responses.

Data Analysis

The interview data were analysed quantitatively and qualitatively. Responses to the closed questions were collated using frequency data to represent the proportion of individuals who identified the need for support, the ratings of importance and effectiveness of support and current sources of support. The responses for open questions were

FIGURE 1
The format of the interview to assess perceptions of support needs (version for the individual).

inductively analysed, whereby the research assistant and primary investigator separately classified responses into categories, which are referred to in this paper as 'issues' associated with support. Coding undertaken independently by two of the researchers was compared and discussed and final coding decisions were made on a consensus basis (Rice & Ezzy, 1999). The issues raised by the 3 respondent groups were compared and contrasted to identify themes emerging from the data.

Results and Discussion

Perceptions of Support Needs

Table 2 presents the proportion of individuals, relatives and case managers identifying support needs across the broad areas of daily living. A general comparison of the three respondent groups' perceptions of support indicated a consensus regarding the need for support in the category of community-based activities. Complete agreement was evident for the support need of attending appointments, which was required for all 8 individuals. There was a lack of consensus between individuals' perceptions and the percep-

tions of relatives and case managers regarding individuals' support needs in the categories of personal and home-based activities, self-organisation and vocational activities and social and psychological well-being. Some exceptions to this, however, involved individuals' need for support with getting dressed, preparing a meal, cleaning the house, paying bills or managing finances and studying, for which responses indicated consensus between the groups.

Relatives and case managers typically perceived the need for individuals to receive support in the areas of forming or maintaining relationships and when feeling bored or lonely. For example, a case manager identified that an individual required support with relationships and explained: "He needs to talk things over and get feedback on how he should behave ... he is learning about relationships and social interaction" (Case Manager 1). In contrast, the individual did not identify the need for support with forming or maintaining relationships, and stated: "No, I can do that quite easily" (Individual 3). However, a number of individuals acknowledged the need for support when feeling upset, which was also perceived by most relatives and case managers. For

TABLE 2

The Proportion of Individuals, Relatives and Case Managers Identifying the Need for Support Across a Range of Support Areas

Categories and areas of support	Individuals with ABI (N = 8)	Relatives (N = 7)	Case managers (for 8 individuals)
Personal care and home-based activities			
Waking up	0%	0%	25%
Getting dressed	12.5%	29%	25%
Having a bath or a shower	12.5%	29%	37.5%
Preparing a meal	87.5%	86%	87.5%
Cleaning your house	75%	86%	75%
Taking medication	37.5%	57%	62.5%
Rehabilitation or normal exercises	25%	14%	50%
Community-based activities			
Doing the grocery shopping	87.5%	100%	87.5%
Travelling around in the community	87.5%	100%	87.5%
Going to leisure and social activities	75%	71%	100%
Attending appointments	100%	100%	100%
Self-organisation/vocational activities			
Planning daily activities	37.5%	71%	62.5%
Remembering to do things	50%	86%	75%
Paying bills or managing finances	75%	86%	75%
Studying	25%	14%	12.5%
Finding or performing work	0%	29%	0%
Social and psychological wellbeing			
Forming or maintaining relationships	25%	86%	75%
Support when feeling upset	62.5%	86%	87.5%
Support when feeling lonely or bored	50%	100%	62.5%

example, one individual reported, “I would not survive in my own skin without the support” (Individual 7). This comment was consistent with his relative’s comments, as follows: “He has a huge history of severe depression — quite a few suicide attempts, several have been near fatal. So, he always needs a huge amount of emotional support in his life” (Relative 7). In general, the findings indicated consensus around individuals’ support needs for community-based activities.

Factors Influencing Perceptions of the Importance of Support

For those areas identified as requiring support, the ratings of importance of support by individuals, relatives and case managers were examined. In general, the areas of support viewed most frequently as “very important” by all 3 groups of respondents included various community-based activities and support when feeling upset or when feeling lonely. Individuals were asked about the reasons for the ratings they provided regarding the importance of support. Their comments suggested that they rated a support need as “not important” or “somewhat important” if they perceived that they had some skills in this area or, alternatively, when they chose other options to receiving support. For example, one individual stated that support with preparing a meal was “not important” because he could buy takeaway food.

Relatives’ ratings of importance of support appeared to be influenced by their perceptions of the individuals’ level of skills, health and well-being, as well as the relatives’ own values. For example, one relative (Relative 5) identified that support with planning daily activities was “some-

what important” because the individual was able to plan some activities. Another relative identified that support with having a bath or shower was ‘very important’ and stated: “I rate hygiene pretty highly. It’s a boost to their self-esteem if they are clean, neat and tidy” (Relative 2). Like relatives, case managers’ ratings appeared to be influenced by the individuals’ level of skill, particularly in the area of cognitive functioning with regard to memory, orientation, motivation and initiation, judgement and decision-making. Additionally, however, case managers’ ratings appeared to be influenced by whether they felt the individual desired or would accept support in that area. For example, one case manager rated support for leisure and social activities as “somewhat important” and explained: “He doesn’t really want to get involved to do different things. Suggestions are made but he’s really not interested” (Case Manager 2). In contrast, the relative for this individual rated support with leisure and social activities as “very important” and stated: “Without people getting him out of that house he would hibernate and lead a lonely and sad life” (Relative 7).

Current Sources of Support

Table 3 presents the sources of support as reported by individuals, relatives and case managers. Overall, there was consensus regarding sources of support between the 3 respondent groups. Respondents perceived that support workers provided support in the majority of areas, depending upon the individual’s needs and circumstances. For 3 individuals, however, family members provided greater support in daily sup-

TABLE 3
The Proportion of Individuals, Relatives and Case Managers Identifying Different Sources of Support

Sources of support	Individuals (N = 8)	Relatives (N = 7)	Case managers (for 8 individuals)
Support workers	100%	100%	100%
Case Managers	50%	86%	88%
Family	88%	100%	88%
Friends	38%	43%	63%
Financial administrators	63%	71%	75%
Psychiatrist or general practitioner	13%	14%	25%
Psychologist	13%	29%	25%
Other services*	38%	57%	50%
No support (i.e., for a specific area of support)	38%	14%	38%

Note: * For example, cleaning services, gym staff, nurses from care agency, staff from residential care agency, police, solicitor, chemist and disability support officers at TAFE.

port activities than support workers. For these individuals, support workers mainly provided support with community access. Some family members identified that the majority of their support was provided over the telephone and involved providing reminders (e.g., for appointments or to take medication) and supporting individuals when they were feeling upset or lonely. Other relatives regularly visited the individual to provide support in areas such as taking medication, paying bills and managing finances (e.g., to provide an allowance) and driving individuals to social and leisure activities.

Most respondents perceived that case managers were also involved in a range of face-to-face and telephone support activities, including planning daily activities, providing prompts and reminders, attending appointments with individuals (i.e., to assist communication between the individual and professional) and providing support when individuals felt upset or lonely. Friends were identified as providing support to some individuals for activities such as travelling in the community, preparing a meal and going to leisure and social activities. As shown in Table 3, most individuals received support from financial administrators to manage their finances. The areas identified where there was “no support” referred to an area where support was needed but not provided by any of the sources. These areas mainly related to social and psychological well-being and assistance with rehabilitation or normal exercise.

Factors Influencing Perceptions of the Effectiveness of Support

The ratings of effectiveness were examined for those areas identified as requiring support by individuals, relatives and case managers. Overall, the areas of support that were typically identified as “very effective” related to community-based activities. The effectiveness of support with appointments is highlighted by the following comments by 3 individuals. “It’s very effective because these people understand what I’ve been through and what I need” (Individual 3); and “They haven’t let me down, so its very effective” (Individual 6); and “I’m normally there on time at appointments ... [support workers provide] verification of what is said and what is not” (Individual 8). Overall, there was no area of support that was consistently rated as “not effective” by the individuals, relatives or case managers.

The individuals’ ratings of the effectiveness of support appeared to be influenced by three related issues. These included the perceived ade-

quacy of support, the belief that support was not always needed and the desire for more involvement in activities. Some individuals, who rated particular areas of support as “somewhat effective”, recognised that there was a limit to what support could achieve. This is illustrated by the following comments: “They can’t remember everything I’m trying to think of” (Individual 5); and, in relation to forming and maintaining relationships, “They don’t have to carry it out to the end. It’s me that’s got to do that” (Individual 2).

Relatives’ ratings of effectiveness of support appeared to be influenced by the availability of support (i.e., the adequacy of support or range of support options) and whether it was considered appropriate to the individual’s needs. For example, one relative stated that support when feeling lonely was “somewhat effective” for an individual and explained, “He has company when his carers are there or if I’m there, or if he’s home here [at his parents’ house]. It would be better if he had friends who would pop in and say hello — he really doesn’t have any of that” (Relative 5). Similarly, case managers’ comments indicated that they perceived support as “very effective” when it was consistently available and flexible, or when the individual had different options for support in a particular area.

Changes in Support

Table 4 presents a summary of the number of changes recommended by participants for the different categories of support. The types of changes in support recommended by individuals included increased support in specific areas (e.g., a visit on a Sunday or more reminders), more variety in community outings (e.g., going to a nightclub) and reduced support and/or greater involvement with activities (e.g., money management and cooking). Particular individuals recommended increased support to provide some relief for relatives in a primary care role, as illustrated by the following request for: “Different people outside the family to take the pressure off mum so I don’t feel like such a burden” (Individual 8). A common finding was that some individuals identified the need for a general change in their circumstances, rather than suggesting an actual change to support. For example, one individual stated: “I’d like my life to be a better life” (Individual 6). A further example of individuals identifying the need for a general change in circumstances, rather than recommending a direct change to support, was the commonly expressed

TABLE 4
A Summary of the Number of Changes in Support Suggested by Individuals, Relatives and Case Managers

Area of support	Number of Changes Identified			
	Individuals	Relatives	Case managers	Totals
Personal care and home-based support (7 areas)	9	7	18	34
Community-based support (4 areas)	9	11	18	38
Self-organisation and vocational activities (5 areas)	5	10	5	20
Social and psychological wellbeing (3 areas)	4	11	17	32

desire for relationships (e.g., for female company or a girlfriend).

The changes to support suggested by relatives involved increasing the amount of support, providing relief for relatives, improving natural support networks (e.g., opportunities to develop friendships), having access to other services (e.g., counselling) and reducing the costs of support. An example of a comment from a relative about providing relief is as follows: “We are concerned that we are getting older; could someone else take over the role of noticing when things need to be done and reminding him, because we have another handicapped son?” (Relative 1). Some relatives identified a specific strategy for assisting individuals to form relationships, as follows: “If we had something called ‘circle of friends’ where a group of friends are built up around a disabled person — that would be great” (Relative 5).

The most common support changes recommended by case managers involved increasing an individual’s independence, providing relief to relatives, improving the variety and choices for social activities, enhancing natural support networks, reducing support costs and increasing access to a range of other services. Case managers often recommended the need for support workers to prompt individuals to be more independent, as demonstrated by the following comment: “I’d like to see [the individual] try public transport. [The individual] and her mother have tried it once but I’d like to see her try it with her support worker — different types of transport and different places” (Case Manager 2). Another common change described by case managers related to individuals having greater access to other services, as highlighted by the following comment:

A lot of the support needs to be better crisis management ... We have experienced difficulty referring to specialised services, the two main ones are drug

and alcohol and mental health services. He’s excluded because of alcohol and his past history with services. Because of his ABI they say it’s an organic problem (Case Manager 3).

Overall, the nature of support changes recommended by the different respondents was relatively similar. Most changes could be classified into the categories of increasing or modifying support from ABICIS, improving access to other services, increasing individuals’ independence and enhancing natural support networks.

Issues Underlying Support Needs

Table 5 presents a summary of the most frequently coded issues associated with support needs, which are displayed in order to reflect how often respondents raised such issues regarding the importance of support and effectiveness of support. “Independence” was used to code responses that related to individuals being able to do things by themselves or with less support, and was most commonly raised by individuals. For relatives and case managers, however, the flexibility of support and individuals’ cognitive limitations, respectively, were the most commonly raised issues. Flexibility of support related to the perceived adequacy and appropriateness of support, and the extent to which support was available from different sources outside the family. As shown in Table 5, a range of different issues were raised across the 3 respondent groups. When the issues raised by the 3 respondent groups were compared and contrasted a number of themes emerged from the data. These themes were labelled “relationships”, “individual choice versus need for support” and “emotional wellbeing”. As the issues raised by the 3 respondent groups were relatively similar for the theme of

emotional well-being, only the first two themes are discussed in this paper.

Relationships

Individuals' relationship issues were raised by all 3 respondent groups and included a lack of relationships (i.e., desire for friendships and partners), feeling socially isolated and lonely and being involved in negative relationships (e.g., conflict with family or peers). However, there were some distinct differences in how relatives and case managers perceived the need for support with relationships compared to individuals. For example, 1 individual identified that support was not needed in this area, while his relative rated this area of support as "very important" and explained: "He is socially isolated, quite disinhibited and impulsive. He says the wrong things and it gets him into trouble and dangerous situations" (Relative 7). His case manager also agreed that this area of support was very important and stated: "He is always saying that he wants to find a partner but the ways he goes about that are inappropriate" (Case Manager 2). Another relative appeared concerned about the people with whom an individual spent time and commented: "He tends to attract the wrong types; people who tend to make use of him and steal from him and rip him off. These people are attracted to him because of his condition" (Relative 2).

Relationship issues were also consistently raised by individuals throughout the interviews. Specifically, when asked about other areas of support (e.g., meal preparation, cleaning and travelling around the community) individuals' responses often included comments about relationships. For example, when discussing grocery shopping, 1 individual stated: "I need a female to help me with my life" (Individual 6). When asked about recommended changes to support for travelling around the community, another individual

said: 'I would be quite happier if there was the occasional female there' (Individual 5).

Individual Choice Versus Need for Support

The need to weigh up individual choice against the need for support appeared to influence a broad range of responses regarding support needs. All respondent groups considered the need for individuals to have choice, but to varying degrees. In general, individuals' responses indicated that they would choose to have more involvement in activities for which they currently receive support. For example, 1 individual felt that he did not have sufficient choice regarding the management of his finances. He stated:

The support is not necessary but it is being imposed on me ... [the financial institution] decided, "we're going to take control of his life whether he likes it or not". I'm in the process of proving to everyone that I can handle it myself (Individual 7).

Whilst relatives often acknowledged individuals' need for choice, they tended to emphasise that an individual's need for support to ensure safety, health and well-being took precedence over the individual's preferences. For example, 1 relative, while acknowledging the individual's need for more social contact, emphasised the importance of support to monitor his inappropriate behaviour and said:

I am his mother — he is 35 years old. I'm sure he would love to go out with a group of guys, but I restrict what he is able to do. I think the carers do too; because of his behaviour, you have to restrict it. (Relative 5)

Case managers appeared to consider individuals' need for choice in recommending levels of support. For example, in relation to support for remembering to do things, one case manager

TABLE 5

A Summary of the Most Consistently Identified Issues Associated with the Support Needs Identified by Individuals, Relatives and Case Managers

Individuals	Relatives	Case managers
Independence	Flexibility of support	Cognitive limitations
Relationships	Emotional well-being	Flexibility of support
Community access	Cognitive limitations	Independence
Emotional wellbeing	Relationships	Choice
Choice	Health	Emotional wellbeing
General acknowledgement of disability	Independence	Relationships

stated: "There's probably things he hasn't told us about so we won't remind him", and elaborated: "You can have too much control if you know everything that's going on in someone's life" (Case Manager 2). In contrast, the relative said: "Without [support to remember to do things] for him, everything falls apart" (Relative 7). Additionally, in relation to preparing a meal, one relative said: "He needs supervision with food preparation ... there are safety issues around the house" (Relative 1). The case manager, however, whilst acknowledging potential safety issues, stated: "Having someone there while he cooks wouldn't be ideal due to the issue of his independence" (Case Manager 3).

Overall, variations in perceptions of long-term support between the 3 respondent groups appeared to be influenced by perceived relationship needs and consideration of individual choice against the need for support.

General Discussion

The main aim of the present study was to explore the perceptions of support of individuals with severe ABI who receive community-based support, as well as the perceptions of family members and case managers. The findings suggested that there was consensus around the importance and effectiveness of support for community-based activities. The recommendations for changes in support suggested that respondents perceived the need for ongoing improvements and flexibility in this priority support area. The two main themes discussed in this paper were relationship issues and the consideration of individual choice versus need for support.

The importance of individuals' perceptions of community-based activities has been previously highlighted by research that examined indicators of community integration and discussed the importance of orientation (i.e., knowing one's way around) and transportation (McColl et al., 1998). In addition, the current research found that relatives and case managers' perceptions coincided with those of the individuals. Some respondents identified that community-based activities were important to prevent loneliness and social isolation, which is an issue identified by previous research (Karlovits & McColl, 1999; Tyerman, 1997). Respondents generally perceived that individuals had only selective needs in the area of personal and home-based care, which is consistent with previous research indicating that personal care needs tend to diminish over time

relative to psychosocial support needs (Fleming et al., 1997).

Relationships emerged as a consistent theme underlying respondents' perceptions of support for a range of areas of daily living. It appears that, although individuals desired improvement in their relationships, they also tended not to acknowledge the need for support with forming and maintaining relationships. Each of the respondent groups discussed the need for natural support networks rather than formal support for relationships. McCluskey, Winkler, Sloan, Callaway and Rowlands (2003) recognised that the development and maintenance of natural supports in the community is a very challenging aspect of community integration, which is often neglected by health professionals. The present study highlighted the need to develop and evaluate interventions for enhancing natural support networks following ABI. To maximise the success of these interventions, the approaches used to develop natural support networks needs to be influenced by, and viewed as acceptable to individuals with ABI. An example of this approach might involve providing *opportunities* for individuals to develop relationships rather than the provision of direct support. Further support in the area of community-based activities, as emphasised by individuals, has the potential to provide such opportunities.

Each respondent group identified some need for increased support in a range of areas. Some of the possible reasons why individuals might not experience the level of support they require, as identified by previous research, relates to the availability of funding and the accessibility of other services for people with ABI (Cameron et al., 2001; McAllister, 1997). However, an additional issue raised in the present study is that respondent groups did not always agree on how an increase in support should occur. Although individuals often recommended an increase in support in specific areas, they also wanted more involvement in activities for which they currently received support. Similarly, individuals' choices and level of independence were important to case managers when recommending changes in support. In contrast, relatives' recommendations for greater availability of support typically focused upon monitoring individuals' behaviour and safety. The case managers' perspective was most consistent with previous research which highlighted the need to structure support in a way that is minimally intrusive and more acceptable to individuals with ABI (McColl et al., 1998).

The variation between respondent groups about perceived support needs is consistent with the observation by McColl et al. (1998) that it can be difficult to balance the perceived needs of the individual, their family and the service provider in providing the appropriate support. The findings of the present study supports that determining this balance is not easy as each respondent expressed legitimate points of view. In order to maximise choice, independence and safety, decisions made regarding individual support plans need to be made based upon the constellation of perspectives of the individual, service provider and family. The present findings also highlight the need for more individuals to have access to long-term specialist services to assist with community reintegration and overall psychosocial functioning. Additional services that need to be coordinated with the lifestyle support plans for some individuals include mental health and substance abuse management and assistance with vocational, social and leisure goals. The present findings indicated that individuals with severe ABI have a range of long-term support needs that may not be fully met by their relatives and a lifestyle support service. The area of support that appeared to be most effectively met by the lifestyle support service was accessing the community for task-orientated purposes.

In conclusion, the purpose of the present study was to explore the perceptions of support of individuals with severe ABI who receive community-based support compared with the perceptions of family members and case managers. There are some limitations to the present study. In particular, the findings are generated from a small and specific sample of individuals with severe ABI receiving support from the same service. The stratified purposeful sampling method used in this study could reasonably be considered representative of the larger ABICIS group according to the criteria used to determine diversity. However, it is not clear whether the findings based upon this sample can be generalised to other populations of people with ABI. While the results are not meant to reflect the experiences of a wide range of people with ABI, the provision of detailed information about participants and their perspectives enables readers to ascertain the relevance of the findings to their own situation. For example, half of the individuals in the sample were diagnosed with co-morbid psychiatric disorders, which may have implications for the nature of support required. The present interview format was designed to identify responses to the specific questions with prompts relating to a range of support needs. It is likely that

alternative questions could be developed to yield different information such as identifying all the people involved in the individuals' support network with prompts to explore the type of support provided. Additionally, a larger sample of individuals with ABI is needed to further examine the patterns that emerged from the present exploratory analysis. Such research could also examine the perceptions of support for individuals receiving support from different sources (e.g., relatives only). Future studies could also examine the issue of support needs in greater depth through use of other qualitative strategies such as participant observation and prolonged engagement.

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References

- Cameron, C., Pirozzo, S. L., & Tooth, L. L. R. (2001). Long-term care of people below age 65 with severe acquired brain injury: Appropriateness of aged care facilities. *Australian and New Zealand Journal of Public Health*, 25, 261–264.
- Crisp, R. (1994). Social reintegration after traumatic brain impairment: A qualitative analysis. *Journal of Applied Rehabilitation Counseling*, 25, 1621.
- Dirette, D. (2002). The development of awareness and the use of compensatory strategies for cognitive deficits. *Brain Injury*, 16, 861–871.
- Fleming, J. M., Strong, J., Ashton, R., & Hassell, M. (1997). A 1-year longitudinal study of severe traumatic brain injury in Australia using the Sickness Impact Profile. *Journal of Head Trauma Rehabilitation*, 12, 27–40.
- Frankel, R. M. (1999). Standards of qualitative research. In B. Crabtree & W. Miller (Eds.), *Doing qualitative research* (2nd ed., pp. 333–346). Thousand Oaks, CA: Sage.
- Harris, J. K. J., Godfrey, H. P. D., Partridge, F., & Knight, R. G. (2001). Caregiver depression following traumatic brain injury. *Brain Injury*, 15, 223–238.
- Hearn, L. (2000). *Acquired brain injury and Queensland: Incidence, prevalence, areas of need, and models of response*. Brain Injury Association

- of Queensland Inc., Milton, Australia: Headway Queensland Publications.
- Hibbard, M. R., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gundersen, N., et al. (2002). Peer support in the community: Initial findings of a monitoring program for individuals with traumatic brain injury and their families. *Journal of Head Trauma Rehabilitation*, 17, 112–131.
- Karlovits, T., & McColl, M. A. (1999). Coping with community reintegration after severe brain injury: A description of stresses and coping strategies. *Brain Injury*, 13, 845–861.
- Kendall, E., Shum, D., Lack, B., Bull, S., & Fee, C. (2001). Coping following traumatic brain injury: The need for contextually sensitive assessment. *Brain Impairment*, 2, 81–96.
- Krefting, L. (1989). Reintegration into the community after head injury: The results of an ethnographic study. *The Occupational Therapy Journal of Research*, 9, 67–83.
- McAllister, T. W. (1997). Evaluation of brain injury related disturbances in community mental health centres. *Community Mental Health Journal*, 33, 341–357.
- McCluskey, A., Winkler, D., Sloan, S., Callaway, L., & Rowlands, A. (2003). *Empowering people with severe disabilities to make friends and develop social networks*. Paper presented at the 26th Annual Conference of the Australian Society for the Study of Brain Impairment, Sydney, Australia.
- McColl, M. A., Carlson, P., Johnston, J., Minnes, P., Shue, K., Davies, D., et al. (1998). The definition of community integration: Perspectives of people with brain injuries. *Brain Injury*, 12, 15–30.
- McColl, M. A., Davies, D., Carlson, P., Johnston, J., Harrick, L., Minnes, P., et al. (1999). Transitions to independent living after ABI. *Brain Injury*, 13, 311–330.
- Morton, M. V., & Wehman, P. (1995). Psychosocial and emotional sequelae of individuals with traumatic brain injury: A literature review and recommendations. *Brain Injury*, 9, 81–92.
- Nochi, M. (1998). "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science and Medicine*, 46, 869–878.
- Paterson, B., & Scott-Findlay, S. (2002). Critical issues in interviewing people with Traumatic brain injury. *Qualitative Health Research*, 12, 399–409.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage Publications.
- Rice, P. L., & Ezzy, D. (1999). *Qualitative research methods*. South Melbourne, Australia: Oxford University Press.
- Seibert, P. S., Reedy, D. P., Hash, J., Webb, A., Stridh-Igo, P., Basom, J., et al. (2002). Brain injury: quality of life's greatest challenge. *Brain Injury*, 16, 837–848.
- Swaine, B. R., Dutil, E., Demers, L., & Gervais, M. (2003). Evaluating clients' perceptions of the quality of head injury rehabilitation services: development and validation of a questionnaire. *Brain Injury*, 17, 575–587.
- Tate, R., Hodgkinson, A., Veerabangsa, A., & Maggiotto, S. (1999). Measuring psychosocial recovery after traumatic brain injury: Psychometric properties of a new scale. *Journal of Head Trauma Rehabilitation*, 14, 543–557.
- Tate, R. L., Lulham, J. M., Broe, G. A., Strettlles, B., Pfaff, A. (1989). Psychosocial outcome for the survivors of severe blunt head injury. The results from a consecutive series of 100 patients. *Journal of Neurology, Neurosurgery and Psychiatry*, 52, 1128–1134.
- Tate, R. L., Pfaff, A., Veerabangsa, A., & Hodgkinson, A. E. (2004). Measuring psychosocial recovery after brain injury: Change versus competency. *Archives of Physical Medicine and Rehabilitation*, 85, 538–545.
- Thomsen, I. V. (1984). Late outcome of very severe blunt head injury trauma: A 10–15 year follow-up. *Journal of Neurology, Neurosurgery and Psychiatry*, 47, 260–268.
- Tyerman, A. (1997). Social bases of community rehabilitation: A review. *Community Rehabilitation Following Acquired Brain Injury*, 1, 29–46.
- Webster, G., Daisley, A., & King, N. (1999). Relationship and family breakdown following acquired brain injury: The role of the rehabilitation team. *Brain Injury*, 13, 593–603.
- Willer, B., & Corrigan, J. D. (1994). Whatever It Takes: A model for community-based services. *Brain Injury*, 8, 647–659.