Factors Affecting the Success of Long-term ABI Rehabilitation

Final Report for Headway Somerset

Authors: Dr Alyson Norman[1], Jack Turner[1], Michael Orman[1]

1: University of Plymouth, School of Psychology

Abstract

Post-acute ABI rehabilitation is incredibly important to the long-term recovery of ABI survivors, with client involvement resulting in a more tailored service. An evaluation of the effectiveness of existing rehabilitation programs was conducted. Inter-rater reliability measures and correlational analysis were used to assess the impact of different demographic factors on the effectiveness of rehabilitation programs. The study predicted that there would be a significant degree of inter-rater reliability in the coding of clients' rehabilitation goals and that the factors of time between injury and rehabilitation, and time since injury would be significantly correlated with rehabilitation success. One-hundred-and-one clients from Headway Somerset, between 19 to 81 years of age, were included in the analysis. Results showed that the inter-rater reliability for statement categorising was acceptable and that rehabilitation success was positively correlated to both age category and time since injury, but not time between injury and referral. Of these two predictors, time since injury was not beneficial to a regression model in comparison to age category, which significantly predicts average rehabilitation success. The results of this study show that both ABI related factors and individual differences between service users play an important role in the success of long term ABI rehabilitation services. Through the personalisation to individuals, improvements to services can be made.

Introduction

Acquired Brain Injury (ABI) is defined as any trauma to the brain experienced since birth (Headway UK, 2014). Since 2005 there has been a 10% increase in ABI hospital admissions in the UK and to date there are around 550 admissions of brain injury in hospitals per 100,000 members of the population (Headway UK, 2014). Despite the importance of in-patient rehabilitation, hospitals only cater for the initial incident of injury and do not provide services beyond the acute phase. ABI can have a variety of more long-term effects. For example, studies have found that ABI injury can lead to increased vulnerability to psychiatric illness, delusional disorder, and personality disturbances (Koponen et al., 2002). Research has also shown that post ABI, individuals are at a higher risk of developing long term depression, which in turn can exacerbate neurological memory deficits caused by the ABI (Bessell et al., 2008). Wider psychological issues include difficulties with substance abuse post-injury (Graham & Cardon, 2008), and suicidality (Simpson & Tate 2002).

Studies have identified that rehabilitation post-injury is a long-term prospect. Studies of individuals two years post-injury have highlighted the ongoing need for support with social skills, and difficulties with a range of cognitive, behavioural and emotional issues (Ponsford et al., 1995). Some research has suggested that these services have a life-long requirement which needs to be met (Olver et al., 1996).

Other long-term effects of ABI include difficulties returning to education (Kennedy et al., 2008) or employment (Huebner et al., 2003), problems with financial management (Dreer et al., 2012) and chronic pain (Hoffman et al., 2007). The need for long-term rehabilitation in these areas is also fundamental to the long-term recovery following ABI. For example, studies have found that occupational therapy for ABI survivors significantly improves their independent functioning in daily life, due

to decreased disability and increased community participation improving quality of life (Huebner et al., 2003). Hartman-Maeir et al*. (2007)* conducted a study comparing the functional status and satisfaction of stroke patients who participated in a community rehabilitation program compared to those who did not. They found that individuals who participated in the rehabilitation programs enrolled in more leisure activities, and were less disabled in basic daily activities when compared to the individuals who did not.

Over the past twenty years rehabilitation services have greatly developed, however, research has highlighted the importance of client involvement in their own rehabilitation to ensure ongoing success (O'Callaghan et al, 2012). The clients at Headway Somerset have been engaged in a new system of rehabilitation involving the use of 'I-statements'. These I-statements allow clients to actively participate in making rehabilitation choices, ensuring that their needs are met and the focus of rehabilitation is directed to the service user's individual needs at any given time. Using the data from Headway Somerset, the aim of this study was to evaluate the I-statement rehabilitation process.

Methods

Participants

One hundred and one (73 male, 28 female, (Mean age = 45.63, age range: 19-81 years) clients of Headway Somerset were included in the analysis of database records on service user rehabilitation. Where possible, information was gathered on type and cause of injury, date of injury and date referral to Headway Somerset.

Procedure

All service user records were extracted from the Headway Somerset databases (both the old version and the new sales force database) and downloaded

into an excel spreadsheet. Data were extracted on service users' age, type and cause of injury, date of injury, date of Headway referral and the number of I-statements that they had completed. I-statement data were gathered from active service users (those still attending Headway) and should be completed every 12 weeks with a review of progress. All data pertaining to reviews were collected along with the outcome of the I-statements (e.g. whether the goal had been completed).

I-Statement data were collected by staff from Headway Somerset using a structured interview with each service user. Data were then entered on the salesforce database. Recorded statements were categorised into one of the following: Communication, engaging with community, social life, life skills, money management, health and wellbeing, family life, managing personal affairs, being safe, work and learning or other. The review completion codes were as follows: Not yet progressed, have made a start, partly achieved, mostly achieved, fully achieved.

Results

The data below outline the characteristics of the Headway Somerset service users (where information was available). Figure 1 shows the age range of clients, Figure two outlines the type of injuries sustained using the Headway UK categories provided on their website, and Table 1 then shows the cause of injury as detailed in the service user referral notes. Table 2 below outlines the mean time since injury across the service users, and the mean time between injury and referral to headway Somerset.
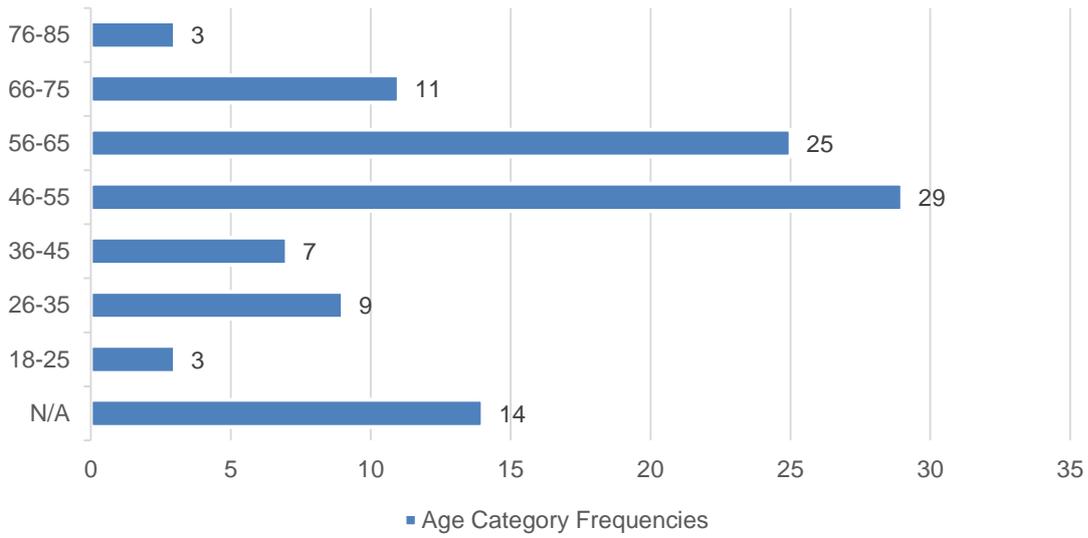
Figure 1: Frequency of clients in each age category
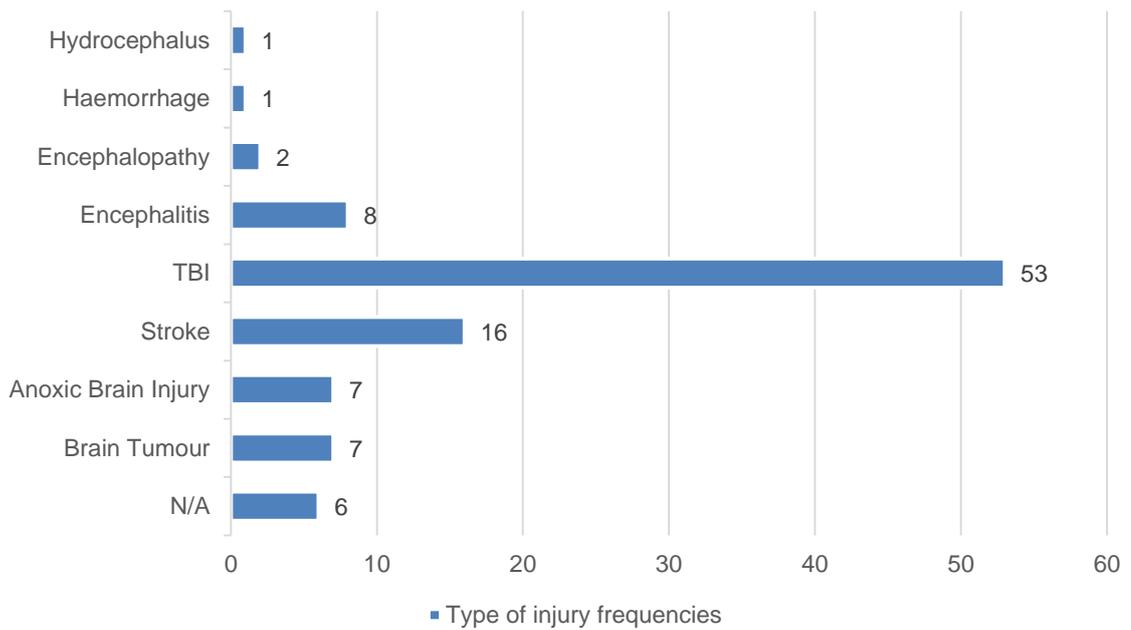
Figure 2: Frequency of injury types across clients.

Table 1: Cause of injury in service users

Cause of injury	Total number of clients
Unclear/Unknown	6
Surgery	4
Cardiac Arrest	4
Stroke	15
CVA	2
RTA	33
Fall	9
Assault	7
Riding Accident	3
Allergic Reaction	1
Meningitis	3
Encephalitis	3
Brain Disease	2
Oxygen Deprivation	2
Removal of Tumour	4
Brain Tumour	1
Haemorrhage	1
Post Viral Neuropathy	1

Table 2: Mean and standard deviation of time since injury and time between injury and referral.

	Mean	Standard Deviation
Time since injury	3.03 years	.96
Time Between Injury and Referral	6.7 years	8.88

Of the active clients present on the database, at the time of analysis at the end of February 2017, 65.28% of I-statements had been completed. Incompletion data were based on any I-statement that had been started but not completed within 12 weeks (and had not been superseded by a newer I-statement during the same time period) and any service users who were active clients but had not received an I-statement assessment. Data were collected on average completion scores for all services users with at least one completed I-statement. The mean self-evaluation score across clients was 11.93 (SD = 11).

A Spearman's Rank correlation was used to determine any relationships between the average completion score for self-evaluations and the population descriptive data. It was found that the average self-evaluation score was positively correlated to both age category (rs= .29, p= <.05) and time since injury (rs= .3, p=<.05). No other correlations were found.

A regression model was used to determine the significance of these correlated items in predicting the average self-evaluation of clients (R^2=.14, F(2,51)=4.17, p=<.05). It was found that of the two predictors, time since injury provided very limited benefit to the regression model (β=.05, p=<.05), whereas age category had a greater influence of the variance in self-evaluation scores (β=.36, p=<.05. This suggests that older clients are more likely to complete I-statements with high self-evaluation scores than younger clients. Clients several years post-injury are also more likely to have higher self-evaluation scores.

As well as analysing the relationships between variable and self-evaluation, the study aimed to identify the reliability of the information gathered in the database, and more specifically the reliability of the I-statement data. To this end, the first authors were given access to the I-statement data without the categories that

indicate the type of rehabilitation requested. The first authors were asked to read the notes recorded from the I-statement and categorise the type of rehabilitation into one of the categories available. On completion of the task, their responses were compared against one another and against the entries made on the database. A Cronbach's alpha statistic of interrater reliability was run on the categories to identify the degree of coding reliability. The statement categorising (coding) showed acceptable reliability (3 items; α=.74), where a score above 0.8 is considered to be good reliability.

Discussion

The study identified that the time between injury and rehabilitation referral was not correlated to the success of rehabilitation exercises as recorded by the I-statement data. However, time since injury was found to be positively correlated, with individuals who were many years post-injury having greater success. This finding provides further evidence that rehabilitation services are important and beneficial to ABI patients and need to occur on a long-term basis (Hare et al 2006). However, it also suggests that current rehabilitation services may not be sufficient or effective when supporting individuals who have more recently acquired a brain injury and have sought out help immediately. This could be, in part, to a poorer understanding in the early stages post-injury of a client's own limitations, or could be indicative of a need to be ready to engage in change, which may come later along the rehabilitation journey. Whilst a correlation was found between time since injury and rehabilitation success, the results also showed an unexpected predictor to the success of rehabilitation in the positive correlation with age. When these two correlations were statistically compared, it was found that in comparison to age, time since injury does not provide any additional variation in the predictive model. Age was positively

correlated with rehabilitation success, suggesting that the older an individual is the more likely they are to succeed in their set rehabilitation goals. This findings could also be explained by insight into one's own limitations and a need to be ready to change.

According to the Cronbach alpha statistical analysis the inter-rater reliability between the Headway Somerset database and two external researchers was reliable. This means that when using the given categories, clients' needs are well determined and recorded by the presiding staff member resulting in a more effective and successful rehabilitation service. Despite this, the value of 0.74 is lower than would be expected in a study such as this and suggests that improvement may need to be made to the way in which rehabilitation goals are categorised. Many of the categories showed a degree of crossover such as money management and managing personal affairs, where the prior could be construed as being encompassed by the latter, or communication and social skills, where again the prior is an element of the latter. In addition to this, the category of being safe was again easily encompassed by health and wellbeing, and whilst it cannot be seen in the results of this report, this category was used only once across all clients, suggesting it may be an unnecessary category. The categories need better definition to ensure that a client's goals are not interpreted as being a different category to that intended by the client, or that other case workers do not identify the goal within a different category. This could result in poor recording of client's rehabilitation goals and inaccuracy in the reported success of those goals.

As shown in the results there was only a 65.28% completion of self-evaluation data. This missing data may have prevented more accurate assessment of the link between various demographic variables and rehabilitation success. It is important

that in the future the database is kept up to date and all I-statement data is collected routinely in a timely fashion. Furthermore, there was considerable missing data amongst the demographic sections of the database. As such, in many instances it was not possible to determine type or cause of injury, time since injury or the time between injury and referral. It was noted that basic demographic information pertaining to age and time since injury was often missing from records. This information should be recoded routinely wherever it is available. This would aid future studies, but also allow Headway Somerset better access to their client group data. In many cases type and cause of injury were missing, and where it was present, the information was often unclear. Currently this information is gathered in a free text box within the database. This should be changed to a drop down menu of possible types and causes. This would make reporting more reliable and make it easier for Headway Somerset to access information on their client group. It was also noted that in the case of clients that had been transferred from the old database to the new, the date of referral was often recorded as the date they were added to the new system. This does not allow for accurate assessment or record keeping, and all accurate referral dates need to be transposed across the systems. Finally, when analysing the I-statement data it was clear that the self-evaluation rating of 1 (not yet progressed) was on occasion being used with client goals that were in fact ongoing. Therefore, it is recommended that a new rating of "ongoing" be added to the evaluation ratings to reflect this status to ensure more accurate recording of data.

To conclude, it was clear that the I-Statement process was allowing greater autonomy to service users in choosing their own rehabilitation goals. Additionally, the system was allowing detailed records to be kept about rehabilitation goals and success. It would appear from the analysis that ABI related factors and individual

differences between service users play an important role in the success of long term ABI rehabilitation services and through the personalisation to individuals these services can be improved.

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