

Success in the workplace following traumatic brain injury: are we evaluating what is most important?

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Abstract

Purpose: Vocational outcome, and in particular full-time paid work, is considered an important indicator of successful rehabilitation following traumatic brain injury (TBI). However it has not been established that these outcomes adequately or accurately represent the values of the people with TBI. This paper describes a study exploring the experiences of individuals who attempted returning to work following TBI, with emphasis on factors that related to perceptions of 'success' or 'failure'.

Method: A phenomenological study, interviewing seven people with moderate to severe TBI was conducted. The interview data were analysed for themes relating to experiences of success or failure in the workplace. Community consultation provided additional perspectives in the interpretation and validation of results.

Results: The results of this study support in part the assumption that paid employment is indicative of success following TBI. Equally prevalent were findings that challenged this assumption, including situations where: (1) return to employment contributed to catastrophic personal events, (2) feelings of success were achieved even though paid employment was not, and (3) success in the workplace was associated with factors other than hours worked or pay earned.

Conclusions: This research suggests that the use of work placement as a measure of successful rehabilitation might misrepresent the perspective of individuals with TBI. A multi-factorial approach to evaluating vocational rehabilitation is

recommended, which incorporates the subjective experience of work.

Introduction

Vocational outcome is frequently described as an important measure of successful rehabilitation following a traumatic brain injury (TBI). It has been stated that vocational status is one of the three outcome categories typically reported on in studies of brain injury rehabilitation.¹ It is suggested that for many people, return-to-work (RTW) is the ultimate measure of the effectiveness of TBI rehabilitation.² Furthermore, certain types of work, in particular paid work, appear to be more valued as outcomes to be achieved and frequently form the basis of measures of vocational outcome.^{3,4} As an example of this, the Vocational Independence Scale⁴ is a five-point ordinal scale that ranks employment status as follows: (1) Unemployed, (2) Sheltered, (3) Supported, (4) Transitional, (5) Competitive, with the inference that the highest level (5) is the 'best' outcome. Such a perspective is not new but has persisted over many decades justified by a belief that such ranking is 'not to demean the importance of sheltered workshops or volunteer activities for brain-injured persons, but (that) involvement in these activities is not synonymous with RTW in the real world of work'⁵ (p. 59).

These statements about the relative value of employment alternatives are based on how 'experts' in the field prioritize certain activities and outcomes. Indeed, this is representative of much of the research on TBI, where the individual with the injury is 'spoken for' by profes-

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sional clinicians, researchers and, in some situations, carers and family. There have been a few exceptions to this where researchers have sought the perspectives of people with TBI on aspects of their lives. For example, qualitative research has been published which presents the opinions of people with TBI on their social relationships and community integration.^{6–8} These papers have provided insights into aspects of TBI such as factors contributing to feelings of social isolation, the impact of societal attitudes on interpersonal relationships, and changes in self-identity following injury. Other studies have investigated the opinions of people with TBI concerning changes in spiritual beliefs following TBI,⁹ cultural variations in understanding of TBI,¹⁰ and the perspectives of women with TBI regarding barriers to accessing rehabilitation services.¹¹ Similar research has not been conducted in the area of vocational rehabilitation however, and this has left a gap in the literature where the values and perspectives of people with TBI are potentially misrepresented.

In common with many Western countries New Zealand has a relatively high incidence of TBI, with approximately 180 per 100 000 population being admitted to hospital with TBI each year.¹² In New Zealand, disability compensation and rehabilitation services for people with TBI are funded through a single public entity, the Accident Compensation Corporation (ACC). Entitlement to ACC funding is available to all people in New Zealand, regardless of ‘fault’ of injury. In exchange people do not have the right to sue for personal injury, other than for exemplary damages. With regard to work and income, ACC provides case management, funds all vocational rehabilitation and related support services, as well as paying weekly compensation of up to 80% of a person’s pre-injury earnings until he or she returns to work. As a result, achieving and sustaining placement of people with TBI back in paid work is of considerable interest.

The aim of this study was to use inductive research methods to uncover a consumer’s perspective on attempting return to work (RTW) following TBI rehabilitation. This paper reports on the findings that relate to perceptions of success or failure in the workplace, and compares these with the assumptions in the current literature that returning to work is indicative of ‘success’ following TBI rehabilitation, with full-time paid employment being the most successful outcome to be achieved.

Method

The local Regional Ethics Committee gave ethical approval for this research. Throughout the study

consultation with community health and disability groups provided direction for the development of research methods, selection of interview participants, validation of key findings and ensured that the research remained relevant to the people involved. From initial community consultation, phenomenology was deemed to be the most relevant research approach to take. Phenomenology has been described as the study of ‘situations in the everyday world from the viewpoint of the experiencing person’¹³ (p. 15). In this research the phenomenological focus was on uncovering the ‘lived experience’ of attempting to return to work following TBI.

Participants were recruited through community-based disability groups and rehabilitation centres. Individuals were invited to participate in the study interviews if they had a past medical history of a discrete traumatic accident resulting in TBI and self-reported symptoms indicating greater than 24 h of loss of memory or consciousness following the accident. Interview participants were also required to be able to give a personal narrative about their attitudes and experience of work or return-to-work following their TBI, even if this was limited by memory impairments or communication difficulties.

At each stage of the study phenomenological research methods¹⁴ were used. Morse and Richards¹⁵ state that the use of a phenomenological theoretical perspective requires the adoption of two key assumptions: the first is that the perceptions of individuals ‘present us with evidence of the world—not as it is thought to be, but as it is lived’¹⁵ (p. 45). In this research it was essential to present the reported experience of people with TBI to ensure the participants’ view of their own vocational rehabilitation was the focus of study rather than professional assumptions about ‘return to work’ or the level of ‘insight’ that participants had into these reported experiences. The second assumption underpinning phenomenology is that human existence in itself is meaningful and of interest,¹⁵ and in the case of this research, is assumed to be of relevance to the practice of vocational rehabilitation.

Participant selection was based initially upon purposeful sampling¹⁵ to ensure participants represented a wide variety and diversity of key characteristics in relation to severity of injury, age, gender, educational level and previous level of work. Theoretical sampling¹⁵ was then adopted to ensure that those perspectives raised in the early interviews could be explored in more depth from a range of different perspectives. People who were unable to represent themselves in any capacity were excluded from the study.

Data collection involved the taping and transcription of open-ended interviews. Minimal prompts were used to elicit information regarding the individuals' injury and their experiences of rehabilitation and return to work. Analysis involved the coding and thematic analysis of interview texts using a constant comparison method. In this way, each transcript is initially read and then coded, with subsequent rereading and coding taking account of other interviews. Emphasis in the analysis focused on the participants' reported experiences, without biasing those views with previously established understandings about vocational rehabilitation. As part of the commitment to consultation, community meetings were arranged during the later stage of data analysis in order to provide feedback on preliminary findings and to contribute positively to the communities who assisted with the research. Data gathering and analysis continued until data saturation had been achieved; in other words, when new interview data revealed 'no new direction, no new questions, and ... no need to sample further'¹⁵ (p. 174).

Several approaches were taken to verify the interview findings. Firstly, to maintain emphasis on the phenomenological approach, a summary of the key findings along with a transcript of the individual's interview was returned to the participants for consideration.¹⁴ Interview participants were then contacted and asked for their opinions regarding the validity of the transcript and initial analysis of the findings, and to challenge the assertion that the themes identified in the analysis were genuinely found in the data. Secondly, community meetings were also used to provide additional perspectives in the interpretation and validation of the results. Thirdly, debriefing with the research supervisors following interviews, triangulation and negative case analysis were employed to establish the credibility and trustworthiness of the findings. Finally, extracts from the interview texts are presented throughout the findings to support and provide credibility for the analysis, although some features of the stories may have been altered to protect the anonymity of participants. Readers of this paper are therefore able to compare the illustrative quotes with their own experiences of living with or working with people with TBI.

Findings

PARTICIPANT CHARACTERISTICS

A sample of four males and three females (total $n = 7$) between the ages of 26–51 years were interviewed. The sample included six New Zealand

Europeans and one person of Maori descent. All interview participants had cognitive impairments and/or memory loss that lasted for over 24 h after their initial injury, with five of the seven participants experiencing post-traumatic amnesia lasting 1 to 3 months. All participants had been admitted to hospital immediately after their injury, however time spent in an in-patient or residential rehabilitation facility ranged from 1 day to 6 months. Of those interviewed, time from the initial injury ranged from 1–1½ years for three participants, 3½ years for one participant, and 7–8 years for the remaining three participants. At the time of the interview two participants were not working, two were engaged in work trials, one was working in part-time paid employment, and two were in full-time paid employment. One of the full-time working participants was self-employed. All participants reported ongoing issues with attention, concentration and fatigue. Six of the seven participants reported experiencing ongoing short-term memory problems. Also reported by individuals were problems associated with tinnitus, noise intolerance, visual impairments, headaches, musculoskeletal pain and contractures some of which were related to secondary injuries. While five of the seven participants had required extensive therapy for physical disabilities resulting from their TBI, all were currently walking unaided and independent with basic activities of daily living such as washing and dressing.

PAID EMPLOYMENT AND 'SUCCESS'

Some of the personal experiences reported on in this study support the assumptions that RTW and paid employment equates with 'success' following recovery from TBI. As might be expected, there was a clear appreciation amongst all those interviewed that one of the primary functions of work was to earn money, and that money meant more control over one's life. As one interviewee put it, 'money gives me the things I need and want in my life.' Such a perspective is represented in the following interview extract:

Extract 1:

R: What is important to you about returning to work? What is important about work for you? ... Why would you do it?

B: Why do I do it? (laughs) Well, income – you've got to have money in this world ...

(Male, mid-40s)

Similarly, dissatisfaction was expressed regarding difficulty returning to one's normal hours of work. Frequently this was associated with fatigue resulting from the TBI. One participant described being surprised and frustrated with her inability to 'get (her) hours up' on her return to work. This ran counter to all her past experiences of being an independent and high-achieving worker who would normally have addressed difficulties by 'working twice as hard'. So to a degree, the findings from these interviews supported the base assumption that people with TBI regard RTW as an important goal to be achieved. Also supported, at least in part, was the assumption that salary and greater hours of work were significant contributing factors to feelings of success or failure in the workplace.

In contrast to this, however, equally prevalent were findings that challenged these base assumptions. These challenges can be divided into three categories: (1) findings that indicated return to full-time paid employment following TBI contributed to catastrophic personal events in the lives of people with TBI, (2) findings that feelings of success could be achieved even when full-time or paid employment was not achieved, and (3) findings that indicated that perceptions of success in the workplace were associated with factors other than hours worked or pay earned.

Catastrophic personal events

Of those interviewed, three reported returning to their previous work roles soon after discharge from hospital. All three maintained a semblance of their former working lives and for a period of time (ranging from 6 months to several years) they all achieved full-time paid employment. However for these individuals this level of work was reported as being achieved at a personal cost. For example, these participants all reported alterations in their non-work life that they had to endure in order to sustain their ongoing work activities. Often this was done in such a way that the difficulties would be hidden (intentionally or unintentionally) from work colleagues. One participant reported that in order for her to maintain her working status she had to live with extreme fatigue and forgo normal personal care activities at home.

Extract 2:

C: I know that one of the reasons that nobody picked up how serious things were is that I would go to bed with all my clothes on, and of course I'd just get up again with all my clothes on, so nobody would know the – how long I'd been asleep ...

(Female, early-50s)

Furthermore, while for these three participants the 'gold standard' of full-time paid employment was ostensibly achieved—in some cases for many years—it was in the long term unsustainable. In these situations interview participants reported experiences of personal catastrophe at the end of their employment. These negative experiences ranged from reaching 'clinical depression', to facing disciplinary action in the workplace, to failing to adapt to a restructured work environment or being fired. For one participant, post-injury employment ended as the result of an assault charge when he seriously harmed a co-worker following a workplace argument. Retrospectively, and with the corroboration later provided by a detailed neuropsychological assessment, this participant attributed these events to poorly managed psychological sequelae of his TBI—in particular, poor management of fatigue, behaviour and hypersensitivity to background noise.

Extract 3:

A: Then this one day someone came in with a little portable stereo, and turned it up loud, I said ... I went right off and walked up, turned it off and he got smart, and basically, he was just a trigger for me to lose it ... I punched him - kicked him, punched him, punched him, kicked him, or whatever ... I don't really remember doing it ... I can remember going – he was, ah, trying to turn, run away from me, and I was thinking what the hell am I doing, as I'm hitting his shoulders ... and then that was the end of my work ... I got, I got sacked on the spot ...

(Male, early-40s)

It could be argued that higher levels of co-ordinated and specialist intervention might have prevented these workplace disasters. Nevertheless, for some individuals, the experience of returning to full-time employment only to then 'fail' in this setting was associated with feelings of 'frustration' and 'defeat'.

Extract 4:

G: I found that after about nine months [of working after injury] I hit, I was hitting clinical depression, and went on anti-depressants and that felt like a huge defeat.

(Female, early-40s)

Extract 5:

C: Um my, the job that I was doing disappeared ... and the job content was actually changing ... a year prior to that, they'd taken disciplinary action against me because I'd made so many muck ups ... that really upset me ... it was like my worst nightmare ... it really, it was like a crushing blow ... I think that that my tears are also, um, because of how deeply it has affected me, I've now got no job, um, and my job was really one thing that I fought tooth and nail to keep.

(Female, early-50s)

Achieving 'success' without achieving full-time or paid employment:

Achievement of personal goals was something all interview participants appeared to value. However for some, the primary focus of vocational rehabilitation was on experiencing a positive and ongoing journey through life following their injury, rather than on achievement of a specific time-dependent outcome. As one participant stated, 'the process is more important to me than the goal'. Some participants, who had not returned to paid employment, described their rehabilitation as a 'success' when compared to possible worse situations. An example of this was one participant who, despite only being capable of undertaking very basic paper filing activities in a work trial for a few hours each week, reported that he felt his rehabilitation had been a success because his mobility had improved to the point where he had been able to attempt the work trial without the use of a wheelchair. In Extract 6 he states that 'it's all down to attitude', suggestive of a perspective where 'success' is a subjective concept, more dependent on personal beliefs about achievement rather than externally imposed values.

Extract 6:

R: How successful do you think your rehab process has been?

D: Quite successful

R: Yes, why do you say that?

D: I'm here ... I'm not bound in a wheelchair ...

cause I used to be bound in a wheelchair ... it's all down to attitude.

(Male, mid-40s)

Valuing 'success' in the workplace on factors other than hours worked or pay earned:

In addition to the number of hours worked and salary earned, other factors were included in the participants' discussions of 'success' in the workplace. For example, feelings of productivity were frequently identified as an important component to 'success'. A sense of having done something 'worthwhile' for one's money was, for some participants, more significant than receiving money regardless of the nature of the work.

Extract 7:

R: And work has always been important to you?

D: Yeah, if I didn't have to earn the money to live—correction ... I just don't like handouts ... I like to ... I like to do something that's worthwhile for my money ...

(Male, mid-40s)

Others described enjoyment related to being meaningfully occupied, and stated that they wanted to have opportunities to be productive regardless of whether or not the work was associated with income. This is not to say that income was irrelevant to the participants. As previously stated the ability to earn money through work was clearly a concept appreciated by all participants. However the personal value derived from working and money earned were at times described as separate issues.

Extract 8:

A: I work because I enjoy working ... I like being occupied, I like working with my hands.

R: Yep, so if somebody gave you a garage and some wood and you had all the money in the world, you would still want to go and make something?

A: Yeah, wouldn't matter how much money I had ... I'd still be doing things ... I'd be making my own furniture, and making things for the family ... I'd probably make things, give them away to

families . . . it's just what I do—what I used to do a lot of, just for the pleasure of doing it . . .

(Male, early-40s)

For a few individuals the relationship between work and vocational identity was paramount. In other words, the way one defined oneself by the type of work one did was considered significantly more important to feelings of 'success' than simply hours of work or amount of pay. The participant in the following extract stated that for her, part-time volunteer work in a professional capacity was more indicative of a successful vocational outcome when compared to full-time paid employment involving unskilled activities. Consequentially, she considered returning to study as more important than returning to her previous non-professional employment.

Extract 9:

R: Why is work important to you now?

E: Well, I suppose, how I, how I view people has a lot to do with it, and how I rank them has a lot to do with the occupation . . . So I also fit myself in the scale as well . . . So I rank professionals above manual workers, kind of like that, it's true . . . If you are not working at all you kind of place yourself almost at the bottom of the scale—so, 'cause you kind of think everybody uses the same scale . . . So you think, well all those professional people are going to look at me and not place me in high esteem.

(Female, mid-20s)

Discussion

Although this study is relatively small and the group interviewed heterogenous, data saturation was achieved. This study raises concerns regarding views of RTW following TBI rehabilitation and presents some challenges to existing theory. For instance while all participants valued returning to full-time paid employment their experiences raise additional considerations in the evaluation of vocational rehabilitation programmes following TBI. Generally speaking, feelings of success or failure were also influenced by the following: the impact of work on their non-working lives, the long-term sustainability of employment, feelings of meaningful productivity and the personal values and beliefs they attached to work activities and to their vocational identity. Therefore, while it is acknowledged that financial

independence and reduced cost to society are important factors when considering outcome, the findings of this study suggest that there are other variables related to work which are considered equally important to people with TBI. This concept in itself is not new. Johnstone *et al.*³ include increased community participation, improved self-worth and psychological well being in addition to financial considerations when identifying the advantages of achieving RTW following TBI. Likewise, in an investigation of the cost effectiveness of supported employment following TBI, Wehman *et al.*¹⁶ state that 'it is imperative that rehabilitation professionals acknowledge the non-monetary benefits of employment' (p. 195), referring to similar psychosocial factors as those identified by Johnstone *et al.*³ However, typical of much of the literature on RTW following TBI, when *measuring* vocational outcomes these authors rely most heavily on tools that emphasize cost benefits or achievement of work placement. In effect, while identifying the value of both subjective (experienced) and objective (observed) aspects, what tends to be measured are only the objective components of RTW. Furthermore, in situations where ordinal scales are used—such as the Vocational Outcome Scale⁴ or the employment component of the Disability Rating Scales¹⁷—judgements are made regarding the relative value of different types of work activities and environments.

Concerns have also been raised regarding the lack of inclusion of subjective experiences in measurements of community integration following brain injury. McColl *et al.*¹⁸ have identified problems with the Community Integration Questionnaire (CIQ) which include the value-dependent ranking of factors related to community integration. They note that the CIQ is built from objectively observable components, with judgements made regarding the relative importance of certain types of community activities and relationships. In comparison, McColl *et al.*'s¹⁸ Community Integration Measure (CIM) is derived from inductive research of the experiences of people with TBI⁶ and, as a result, is a measure which reflects the subjective perspectives of individuals with TBI, independent of the values of health funders or rehabilitation providers.

Research into work satisfaction for populations of people with other disabilities, such as spinal cord injury (SCI), has also explored the value of subjective perspectives of job satisfaction.^{19, 20} Ville and Ravaud²⁰ reported that people with paraplegia regard work as a source of personal fulfilment and social recognition, indeed more so than non-disabled people. This finding is similar to the relationship between feelings of productivity, personal identity and employment that were expressed by the

interview participants in this research. However Ville and Ravaud²⁰ also report that individuals with paraplegia consider it is just as easy to find similar self-fulfilment in non-vocational activities. Extending this concept further, the experience of some individuals with TBI in this research suggests that when in the 'wrong' job with the wrong level of disability support it is possible that the experience of attempting work can be ultimately detrimental to feelings of self-fulfilment or self-worth.

Another issue arising from the interview findings concerns reliance on measurement of vocational outcome at a single point in time. Of the people interviewed, several reported a fragmented employment history after their injuries, moving through a series of jobs or job trials with varying degrees of achievement. This implies that when evaluating success in the workplace an emphasis on continuity of employment is of value. Studies that focus on point-in-time measurement of vocational outcome following TBI^{21, 22} may present misleading information about sustainability of employment. Also noteworthy was the variation of time in full-time paid work before workplace problems reached a crisis-point resulting in termination of the employment. For two of the interview participants, work was maintained for three or more years (either as a single job or a series of jobs) before circumstances forced them out of their employment. This suggests that when evaluating 'long-term' vocational outcome following TBI, collecting data after one to two years^{21, 22} may be insufficient to give a true indication of lifetime employability. One recent paper which addresses both these methodological concerns is the study by Wehman *et al.*¹⁶ This study presents the results of a cost-benefit analysis of a supported employment programme for people with TBI, and uses length of employment and total gross earnings for the entire duration of employment as an indication of vocational outcome over a 14-year period.

A further implication related to this is the need for ongoing vocational support for people with TBI. If vocational rehabilitation services are evaluated (or indeed remunerated) on the achievement of work placement rather than the durability of that employment, there is a risk that long-term vocational support for people with TBI will not be provided when needed. Wehman *et al.*'s¹⁶ study on supported employment provides some evidence for the potential cost-effectiveness of long-term rehabilitation services. However, it is possible that people with TBI who are in full-time, competitive employment (or other forms of productive activity such as homemaking, parenting or volunteer work) also need opportunities for ongoing disability

support. Some of the workplace problems reported by the interview participants related to difficulties they experienced adapting to a changing work environment. One participant described losing her job after a series of 'performance reviews' followed by organizational restructuring. Another discussed the challenges they faced not only relearning previous work skills, but also keeping current with new workplace technologies that continued to be developed. The findings suggests that people with TBI may well benefit from accessing rehabilitation or work support services at intervals throughout their working lives, particularly at times of individual role or organization change.

For health funders and rehabilitation providers, achievement of work placement is seen as an indicator of the economic value of the services purchased and provided. Work is viewed as a 'goal' to be achieved—an outcome that demonstrates the success (or failure) of rehabilitation services for people with TBI. Reviewing the findings of this study it can be suggested that people with TBI themselves do not necessarily consider the amount of money they earn as the most important factor by which to evaluate the success of their rehabilitation. Of those interviewed, the opportunity to attempt work activities was often described as being more important than achievement of a specific vocational objective—'the process' being more important than 'the goal'. This may in part reflect the weekly compensation that is automatically available to all people with TBI in New Zealand once ACC entitlement has been established. Other countries with different insurance structures and compensation schemes may find different results in this respect. However, the finding from this study that may be more universal relates to the common desire to have opportunities to achieve one's own maximum potential. As an illustration of this, one participant from this study described frustration with her rehabilitation provider's emphasis on timed goals, stating that while she felt she was making progress in her rehabilitation, her services had been cut short because of her inability to achieve a set objective within a pre-specified timeframe.

Previous research investigating the values of people with disability has also challenged the notion of 'goal attainment' as the most important factor when evaluating the success of rehabilitation services.²³ In a qualitative investigation of the perspectives of people with arthritis, a notion of 'taking charge' was identified as the most important outcome desired by many of those studied.²³ As described by McPherson *et al.*,²³ the concept of 'taking charge' refers not only to the person being actively involved in aspects of their life that are

most important to them, but also to 'taking charge' by way of delegation of some activities and decisions to others. The current study suggests that assisting clients and patients to 'take charge' of their vocational status is complex and may yield consequences that are at odds with an externally set goal of full-time employment. This concept relates to some definitions of quality of life that emphasize the need for sufficient opportunities to make choices in one's life and the need to have control over one's environment.¹⁹

While the development of alternative measurement tools is outside the scope of this paper, some recommendations can be made regarding future research into the effectiveness of vocational rehabilitation programmes for people with TBI. The primary recommendation is that further effort is required to develop measures that reflect subjective evaluations of job satisfaction for people with TBI. To be valid, such a measure may need to be able to reflect the impact of an individual's current employment situation on his or her feelings of meaningful productivity, self-worth associated with vocational identity, perceived ability to take charge of his or her career, and the perceived impact of his or her employment on the quality of his or her non-work life. Furthermore, it is suggested that research needs to consider the continuity and sustainability of employment for people with TBI over a number of years. Research that reports vocational outcomes at a single point in time ought to be conservative in its conclusions.

Conclusion

People with TBI do regard RTW as an important achievement. However, like all other members of the community, people with TBI need more than just a job. Work needs to contribute to feelings of meaningful productivity. It needs to be stimulating, creating a positive sense of identity and self-worth without compromising success in non-work life. When developing evaluation strategies, these subjective factors should be included in measurement design. The perspectives of people with TBI should be considered when choosing tools to evaluate the quality of rehabilitation service provided.

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