

# The Participants' Perspective on a Cognitive Rehabilitation Program Following Traumatic Brain Injury

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## Abstract

Given the recommendations for evidence-based treatment practice, rehabilitation programs are typically evaluated using standardized objective measures of pre- and post-treatment performance. However, the potentially informative opinions and perspectives of the participants themselves are not reported. This paper sought to redress this imbalance by using a semi-structured telephone interview to gather feedback from 19 participants who had undergone a group-based eight-week cognitive rehabilitation program to improve attentional impairment following traumatic brain injury (TBI). The program incorporated cognitive training using an action video game and psycho-education, including a workbook for developing compensatory skills. Findings indicated that the majority of participants found the program to be a positive experience, resulting in self-perceived skill development that generalized beyond the training context. Participants particularly valued the social aspects of the rehabilitation program and reported benefiting from their interactions with the other group members. Most enjoyed the action video game playing, although for some, the opportunity to select between a set of different games rather than playing the single game that featured in the program would have been more appropriate. The majority of participants also found the workbook helpful. Other useful suggestions included extending the program to 10-12 weeks, increasing group size, developing more of a 'take away' aspect of the program to be administered at home, and formalizing the 'mentoring' roles that emerged in the group.

**Keywords:** cognitive rehabilitation, cognitive remediation, traumatic brain injury, attention, patient perspective

## 1. Introduction

Traumatic Brain Injury (TBI) is a major cause of impairment and disability and research into rehabilitating these deficits is an area of increasing interest. Research to date has focused primarily on systematically reviewing and empirically evaluating cognitive rehabilitation (CR) programs (Carney et al., 1999; Chesnut et al., 1999; Cicerone et al., 2000; Cicerone et al., 2005). However, while evaluating the effectiveness of a program through measuring objective changes in test performance and other interviewer-based measures is crucial, some potentially valuable information can be lost, especially with regard to the subjective experiences of the persons undergoing rehabilitation. This information is highly valuable to researchers and clinicians alike when developing rehabilitation programs. Given the often ignored value of the perspectives of participants in a rehabilitation program, this paper represents a shift of focus to highlight the subjective opinions of the participants.

During the process of empirical research, clinicians and researchers often become aware of the perspectives of the participants and these may be reported anecdotally, but they are rarely systematically recorded so that quantitative data can be reported. While anecdotal reports can be valuable, the inclusion of such quantifiable data, even if in the form of simple frequencies, is important to advance the scientific evaluation of programs and also to allow the replication of methodology, as well as to extend evaluation of the generalization of post-treatment improvements. However, such data is also very important for a number of other reasons. First, the participants' opinions of the strengths and weaknesses of a particular program, plus their ideas to improve on the existing program, may guide further modifications to improve future application of CR programs in the brain injury units. Second, it is important to know how participants perceive the impact of the program on their daily functioning so as to better understand generalization. For example, some behavioural changes post-treatment might be

automatic while others will require intentional effort to bring about the changes, for example, in new activities being attempted or in old activities being resumed. It is unlikely that the patients will intentionally try to change such behaviours post-treatment if they do not believe that the program has had an effect on their functional abilities. Additionally, clinical experience has been that participants in rehabilitation programs can experience negative emotions at the cessation of programs due to the withdrawal of treatment and contact with others. It is important to identify such cases so as to intervene.

For the aforementioned reasons, the current study used a brief semi-structured telephone survey to evaluate the participants' thoughts on their participation in a CR program to rehabilitate attentional deficits following TBI using action video-game playing and a psycho-education component, including a workbook for developing compensatory skills (see Valkili & Langdon, submitted, for full details). In brief, participants had attended a two-hour group rehabilitation session at their Brain Injury Unit (BIU) once a week for eight weeks. Groups consisted of four to five participants. In each session participants played "Medal of Honor: Rising Sun" (MoHRS; Electronic Arts, 2003) for approximately three-quarters of the session, and the remainder of the time was dedicated to a psycho-education program addressing some of the common consequences of brain injury and introducing compensatory strategies. The survey being reported here was administered over the phone following completion of this program and the pre/post treatment assessments.

## 2. Method

In the treatment study under specific investigation, 31 participants were recruited from two brain injury rehabilitation units in Sydney, Australia. Eleven participants dropped out of the treatment study before completion (five in the original treatment group and six in the waitlist group who were later offered treatment after completion of the formal post-treatment assessment phase), leaving 20 participants to complete the survey. Nineteen out of the 20 participants agreed to complete the survey, and one participant could not be contacted. All 19 had thus undergone the treatment program, were male, aged between 18 and 65 years old, and had sustained a TBI at least one year prior to the program.

A brief phone survey was administered within 30 days of completing the eight-week CR program. The survey was administered by a third party researcher (not the researcher who ran the groups) to allow the participants to express their views openly. The survey was structured to allow closed- and open-ended responses. The following questions were asked of each participant:

- What did you like best about the video game research?
- What did you like about the video game "Medal of Honor"?
- What did you like about being part of a group each week?
- Did you find the workbook helpful?
- Do you think it improved any of your skills/helped you learn other things?
- Do you think those skills will be useful in other things you do?
- What did you like least about the video game research?
- How did you find the group of people you were with?
- How did you manage travelling in to the BIU each week?
- Was eight weeks long enough, or too long?
- Any suggestions for improvements to the video game group that you would like to make?
- Location
- Duration (number of weeks, and two-hour sessions)
- Number in group
- Any other comments that you would like to make? Prompt- how did you feel when the group ended?
- Would you like to keep being part of a video game group?
- If yes, would you want to do this yourself at home, or as part of a group?
- Where do you think is a good place for a group to meet to play video games? (prompts: local library, Brain Injury Unit, Brain Injury Association)
- Would you like to take part in a research project like this in the future?

- Can you please tell me the reason/s you would/wouldn't like to take part?

Responses were coded, as appropriate, and simple frequencies and percentages are reported.

### 3. Results

- What did you like best about the video game research?

A total of 26.3% of participants referred to the social or entertainment aspects of the CR program, indicating that they enjoyed meeting new people, getting out of the house and having fun. Another 21.1% reported enjoying the content of the video game most. Another 15.8% referred to the cognitive benefits of training, and 15.8% gave very general positive responses such as "everything". Only 10.5% gave a negative response, such as "nothing" or indicating that it was a waste of time. One participant indicated monetary gain as the best thing about the program and one did not respond. Table 1 below summarises some of the responses for each categorisation.

Table 1. Responses to the question "What did you like best about the video game research?"

	Frequency	Sample Responses
Social or entertainment value	5	<i>"Meeting new people"</i> <i>"Enjoyable"</i> <i>"Got me out of the house"</i> <i>"It was different, relaxing"</i> <i>"I got to have fun"</i>
Reference to the Video Game	4	<i>"It was a medium I was familiar with. I spend a lot of time playing computers"</i> <i>"Playing the shooting games"</i> <i>"It was challenging to get over the bridge and to the other side"</i> <i>"Didn't die (in the video game), could keep coming back to life"</i>
Cognitive Training	3	<i>"Taught me different mental skills, anger management, better thinking skills"</i> <i>"Helpful to get on everyday and teach strategies. Exercise brain"</i> <i>"Things were actually explained to me. It provided education about my injury"</i>
General Response	Positive 3	<i>"Everything"</i> <i>"Alex was good at explaining things"</i> <i>"It was a bit hard and a bit easy (it was a challenge but also got some things right)"</i>
Negative Response	2	<i>"Was a waste of time"</i> <i>"Nothing- I had a breakdown halfway through. Couldn't handle things"</i>
Monetary Gain	1	<i>"Got paid to do it"</i>
No response	1	

- What did you like about the video game "Medal of Honor"?

When asked about the video game in particular, 36.8% of participants said they liked the game content, such as the shooting action and the challenge of trying to get to the next level. Another 21.1% reported liking the game for the rehabilitation outcomes, for example, commenting on the challenges and the cognitive exercise it provided. And 10.5% liked the game but provided general reasons, such as it being a different thing to do and the competitive nature of it. Only 21.1% reported not liking the game, for example, finding it too hard or not liking the action content. Table 2 below summarises some of the responses for each categorisation.

Table 2. Responses to the question "What did you like about the video game Medal of Honour?"

	Frequency	Sample Responses
Positive Response: Game Related	7	<i>"Didn't die (in the video game), could keep coming back to life"</i> <i>"Trying to get to the next level"</i> <i>"It was a first person shooter, I have played these games my entire life"</i> <i>"It was good I like shooting games"</i>

		<i>"I got to shoot people"</i>
		<i>"It had strategy and had to figure out who to shoot"</i>
		<i>"The game in general and playing it with others"</i>
Positive Response: Rehabilitation Related	4	<i>"Good - could practice what I learnt each week"</i>
		<i>"Challenged me"</i>
		<i>"Enjoyed- good works the brain. But too difficult, get frustrated"</i>
		<i>"A good thinking game"</i>
Negative response	4	<i>"Didn't like the second part of the game as it was too hard but other part was good"</i>
		<i>"Not into video games"</i>
		<i>"Didn't like it, difficult to figure out"</i>
		<i>"Hated it- Worst game to play given my situation, i.e., thoughts of violence"</i>
Positive Response: General	2	<i>"Different thing to do"</i>
		<i>"Very competitive"</i>
No response	2	

- What did you like about being part of a group each week?

When asked specifically about the group, 57.9% responded positively to the social aspect of the group, identifying relating to others, learning about others, helping others and making friends as their favourite part of being in the group; 21.1% responded positively to the personal benefit that came from working in a group, such as realising they were not alone and striving to reach the level others were at; 5.3% responded positively but very generally ("It was good"). Only 10.5% responded negatively about the group, saying that they didn't care or didn't like anything about the group. Table 3 below summarises some of the responses for each categorisation.

Table 3. Responses to the question "What did you like about being part of a group each week?"

	Frequency	Sample Answers
Social	11	<i>"Relating to other people in the group. Thinking better as a result of the program - thinking before speaking, answering questions better"</i>
		<i>"Finding out different things about others"</i>
		<i>"Talking to new people"</i>
		<i>"Loved it- loved helping each other out"</i>
		<i>"Like working with family - talking to others, social"</i>
		<i>"Got to meet other people with a brain injury"</i>
		<i>"Made friends"</i>
		<i>"Socialising"</i>
		<i>"Enjoy the game together"</i>
		<i>"It helps you more and makes the experience entertaining"</i>
		<i>"Good to relax with other people and help others"</i>
Positive Response: Benefit to self	4	<i>"Help clarify things and explain why I snap at people"</i>
		<i>"Realised I'm not alone"</i>
		<i>"Didn't mind. There were some nice people there, better than doing it alone"</i>
		<i>"Good. I was the worst one there. I did my best. I strived to get to their level"</i>
Positive Response: General	1	<i>"It was good"</i>
Negative Response	2	<i>"Nothing"</i>
		<i>"I didn't care about the group thing. I just went every week. It came down to how you played by yourself"</i>
No response	1	

- Did you find the workbook helpful?

Fifteen of nineteen, or 78.9% of participants reported finding the workbook helpful. Another 10.5% (2/19) reported that it was not helpful, and 10.5% (2/19) were neutral in their response.

- *Do you think it improved any of your skills/helped you learn other things?*

When asked about any improvement in skills gained from training, 78.9% (15/19) identified benefits such as concentration, organisation and managing tiredness, while 10.5% (2/19) of participants did not see any benefits from the training. One participant identified worsening skills (5.3%) and another one (5.3%) was uncertain. Table 4 provides some examples of the positive responses.

Table 4. Responses to the question “Do you think it improved any of your skills/helped you learn other things?”

	Frequency	Sample Responses
Positive Response:	15	<i>“Little bit - concentration, ability to get up and get organised”</i> <i>“Helped with attitude and getting less upset”</i> <i>“I think so- help understand and manage my tiredness”</i> <i>“Yes helped exercise my brain”</i> <i>“Yes I realised I’m not alone and I’m one of the lucky ones”</i> <i>“Definitely - benefit wasn’t just from the game itself”</i> <i>“Helped because it was stimulating and challenging”</i>

- *Do you think those skills will be useful in other things you do?*

With regard to the generalisation of skills, 73.5% (14/19) identified cognitive and emotional benefits from training, while 21.1% (4/19) did not think they would derive any benefit from the treatment. One participant (5.3%) identified bowling as a specific improved skill. Table 5 below provides examples of the positive responses.

Table 5. Responses to the question “Do you think those skills will be useful in other things you do?”

	Frequency	Sample Response
Positive Response: Cognitive and Emotional	14	<i>“Yes - can plan things better”</i> <i>“Yes - problem-solving”</i> <i>“Memory and got my brain going”</i> <i>“When driving and helped with strategies and patience”</i> <i>“Yes, improved the way I approach situations and behave in them”</i> <i>“Anger management, dealing with things, stopping to think before I do or say things”</i> <i>“Makes things easier and teach to become more patient in everyday life. Help me socialise more after head injury”</i> <i>“It helped me to catch dropped objects. Faster reaction times”</i> <i>“Due to the group environment, I knew I could catch up. It helped me with perseverance”</i> <i>“Yes helped me understand things so I can change before I react”</i>

- *What did you like least about the video game research?*

When asked about what they least liked, 52.6% (10/19) could not identify anything they did not like; and 21.1% (4/19) identified the particular video game as their least favourite. One participant (5.3%) ‘hated’ the pre- and post-assessments, while one participant (5.3%) did not like the travel involved to attend and one participant (5.3%) found the furniture in the testing room used for the assessments uncomfortable. Two (10.6%) responded ‘don’t know’. Table 6 below provides examples of the negative game comments.

Table 6. Responses to the question “What did you like least about the video game research?”

	Frequency	Sample Responses
The Video	4	<i>“Sometimes the game went too fast”</i> <i>“When I got shot I didn’t like to go back to the beginning. It was frustrating to go</i>

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Game	<i>back and start from the beginning”</i> <i>“The video game”</i> <i>“Can’t remember. Maybe a variety of games would have been good, not just one game. Maybe a puzzle game would be helpful”</i>
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- How did you find the group of people you were with?

When asked about the other people who were in the group, 78.9% (15/19) of people responded positively, indicating that they enjoyed and benefited from the group component of the program. Another 15.8% (3/19) responded negatively to the group component; two of these responses regarded being bothered by a single other participant. One person (5.6%) failed to respond.

- How did you manage travelling in to the BIU each week?

Regarding travel, 78.9% (15/19) did not report any problem in travelling to their BIU to take part. The remaining 21.1% (4/19) reported a negative reaction to the travel; for two of these participants parking was the main problem.

- Was 8 weeks long enough, or too long?

Eight weeks was seen as an appropriate amount of time by 63.2% (12/19) of participants. Another 31.5% (6/19) of participants saw eight weeks as not long enough, and one participant (5.3%) did not know.

- Any suggestions for improvements to the video game group that you would like to make?

Of the participants, 68.4% (15/19) had no suggestions. Another 10.5% (2/19) suggested using some other game and 10.5% (2/19) suggested more sessions.

- Location

One participant would have preferred the location of the program closer to home and one failed to respond. The remaining participants (17/19: 89%) were happy with the program being held at their BIU.

- Duration

Five of nineteen, or 26.3%, of participants believed the duration of the program was too short. Two responded ‘don’t know’. The majority (12/19: 63%) were happy with two-hour sessions for eight weeks.

- Number in group

A total of 36.8% of the participants felt the group could have been larger. One responded ‘don’t know’ and the majority (11/19: 58%) were happy with four to five people per group.

- Any other comments that you would like to make? Prompt- how did you feel when the group ended?

Five of nineteen, or 26.3%, of participants reported positive feelings at the cessation of the program; these people generally felt they had benefited from the program and expressed no loss or sadness at not attending group after its completion. Another 21.1% (4/19) expressed that they felt sadness at cessation of the program. Other comments included requests to keep the program going, developing a take-home version, and to make the workbook more relevant to the patients’ lives. The remaining 36.8% (7/19) of participants had no comment.

- Would you like to keep being part of a video game group?

A majority of 84.2% (16/19) of participants would have liked to continue being a part of the group and 15.8% (3/19) did not.

- If yes, would you want to do this yourself at home, or as part of a group?

Of those who wished to continue, 57.9% (11/19) wished to participate as part of the group. Another 15.5% (3/19) were happy with either option, and 10.5% (2/19) of participants preferred to continue at home.

- Where do you think is a good place for a group to meet to play video games? (prompts: local library, BIU, Brain Injury Association: BIA)

A total of 84.2% (16/19) of participants identified the hospital’s BIU as a preferable place to hold the rehabilitation program. One participant preferred to do it at home and two responded ‘don’t know’.

- Would you like to take part in a research project like this in the future?

A majority of 89.5% (17/19) of participants affirmed wanting to take part in another research project such as this

one. One participant did not wish to participate and one was neutral.

- Can you please tell me the reason/s you would/wouldn't like to take part?

A total of 47.4% (9/19) referred to helping themselves or helping others in their reason for wanting to take part again. Another 31.6% (6/19) indicated general positivity such as having fun or keeping occupied. Of the three who reported not wanting to continue, one reported disliking the action video game used in the program, one felt uncomfortable about not knowing the others in the group, and one didn't like the necessary time investment. Table 7 below provides examples of the positive responses.

Table 7. Responses to the question "Can you please tell me the reason/s you would/wouldn't like to take part?"

	Frequency	Sample Response
Positive Response : Helping Self/Others	9	<p>"Good research because it helps others"</p> <p>"Can benefit me and help others with their cognitive thinking"</p> <p>"Because I can help people"</p> <p>"Try and help myself get better"</p> <p>"Helps understand... my understanding of things and how to improve or make things better (re: injury)"</p> <p>"Helped me in small ways, sees improvements as valuable"</p> <p>"Help self and help others"</p> <p>"It was fun to be with other people and learn stuff"</p>
Positive Response : General	6	<p>"Keeps you occupied"</p> <p>"Because I've finished school and want to do more stuff"</p> <p>"Fun and meet new people"</p>

#### 4. Discussion

This study aimed to collect and report in quantifiable form the valuable opinions of participants who took part in an eight-week CR program. It must be acknowledged that the uncontrolled and qualitative nature of this research leaves it vulnerable to error and bias. For example, it may be the case that following an investment of time in the program, participants felt obliged to provide positive responses. This research implemented some techniques to minimise the impact of bias, such as utilising independent interviewers, unknown to the participants, to administer the questionnaires. However, the interpretation of the findings should remain tentative and sceptical. There is much to be gained from the experiences and opinions of our research participants and these inherent limitations do not justify the lack of investigation and publication of these perspectives.

In summary, most participants expressed positive feelings overall, identified improvement in their skills following training, identified gains outside the training context, and said they would like to participate in a similar program again. We have collated two lists guided by the feedback from the participants: 1) the elements we would recommend implementing in any future CR program and 2) the elements to reconsider in any new program design.

##### 4.1 Recommendations for Future Programs

The group format: Participants reported that the social aspects of the program were a very important part of the experience. Not only was the group reported to provide enjoyment and entertainment; it also assisted participants to deal with the emotional consequences of the brain injury, i.e., participants reported feeling less isolated and realizing that they were not alone. Of the participants who would like to continue with CR, the vast majority wished to continue as part of a group.

The workbook: The majority of participants found the workbook helpful. One participant suggested making the workbook more relevant to the participants' lives. The current literature affirms that the more closely the activities used in rehabilitation programs resemble everyday activities, the more likely training is to generalise. Therefore, future programs based on action video-gaming and incorporating psycho-education may be more flexible in including tasks that more closely resemble the participants' functional requirements.

Located in the hospital BIU: The majority of participants were happy with the program being run at their local brain injury unit.

#### 4.2 Redesigning Future Programs

The video game (*Medal of Honor: Rising Sun*): One-fifth of the participants identified the particular video game used as their least liked part of the program. It was possibly too difficult, too fast, and frustrating in that the nature of this game is such that participants had to return to the beginning of a level every time their character died. While games in the ‘action’ genre are recommended to remediate attention deficits, a variety of such games might be offered in future programs of this type, as suggested by one participant.

The duration could potentially be extended from eight weeks to 10 or 12 weeks. A number of participants felt the program was too short and suggested more sessions, although programs that become too lengthy increase risk of drop-outs.

Larger groups: A proportion of respondents suggested larger group numbers. If manageable, a larger group could be considered, with an additional group leader.

A ‘take away’ program to be administered at home. One participant reported that they would have preferred to do the program at home alone. Others suggested continuing the program at home after it ended at the brain injury unit.

Enhancing the ‘mentoring’ aspects of the program: Many participants enjoyed assisting other participants with game play and also enjoyed sharing experiences and providing moral support. These co-mentoring aspects of the program could be formalized and encouraged.

There was one participant who had a fairly negative experience. He reported increased thoughts of violence following the action video game and did not report any benefit from the program. More extensive psychological and clinical screening should be considered to exclude participants who have violent or aggressive tendencies and/or possible paranoia associated with exposure to violent action, albeit in the context of a video game

In sum, from the participants’ perspective, the program was a positive experience, resulted in skill development, and generalized benefits beyond the training context. Participants reported enjoying and benefiting from the social nature of the group setting and finding the workbook helpful. Most also reported enjoying the video game activity, although for some a selection of different action games would have been more appropriate and additional screening to match participant to game or to exclude may be worthwhile. Most rewarding was that the vast majority would like to participate in a similar group rehabilitation program again.

#### References

- Carney, N., Chesnut, R. M., Maynard, H., Mann, N. C., Patterson, P., & Helfand, M. (1999). Effect of cognitive rehabilitation on outcomes for persons with traumatic brain injury: A systematic review. *J. Head Trauma Rehabil*, 14(3), 277-307. <http://dx.doi.org.acs.hcn.com.au/10.1097/00001199-199906000-00008>
- Chesnut, R. M., Carney, N., Maynard, H., Mann, N. C., Patterson, P., & Helfand, M. (1999). Summary report: evidence for the effectiveness of rehabilitation for persons with traumatic brain injury. *J. Head Trauma Rehabil*, 14(2), 176-188. <http://dx.doi.org.acs.hcn.com.au/10.1097/00001199-199904000-00007>
- Cicerone, K. D., Dahlberg, C., Kalmar, K., Langenbahn, D. M., Malec, J. F., ... Bergquist, T. F. (2000). Evidence-based cognitive rehabilitation: Recommendations for clinical practice. *Arch Phys Med Rehabil*, 81(12), 1596-1615. <http://dx.doi.org/10.1053/apmr.2000.19240>
- Cicerone, K. D., Dahlberg, C., Malec, J. F., Langenbahn, D. M., Felicetti, T., ... Kneipp, S. (2005). Evidence-based cognitive rehabilitation: updated review of the literature from 1998 through 2002. *Arch Phys Med Rehabil*, 86(8), 1681-1692. <http://dx.doi.org/10.1016/j.apmr.2005.03.024>

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