PROFESSIONAL DOCTORATES

Impaired awareness following acquired brain injury : conceptual, emotional and treatment considerations

Roberts, Craig

Award date:
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Bangor University

IMPAIRED AWARENESS FOLLOWING ACQUIRED BRAIN INJURY:

CONCEPTUAL, EMOTIONAL AND TREATMENT CONSIDERATIONS

CRAIG BRENDAN ROBERTS

UNIVERSITY OF WALES, BANGOR

Thesis submitted in partial fulfilment of the requirements of the degree of Doctorate in Clinical Psychology (D Clin Psy)

January 2005

TEXT BOUND INTO

THE SPINE

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Feedback of brain-imaging findings: Effect on impaired awareness and mood in acquired brain injury

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SUMMARY

Impaired awareness following acquired brain injury: conceptual, emotional and treatment considerations

Acquired brain injury (ABI) frequently results in a characteristic spectrum of physical, cognitive, and behavioural consequences. Individuals with ABI are often unable to appreciate these consequences and comprehend the influence of these deficits on everyday life. These individuals are said to have impaired awareness. A selective overview of the literature on impaired awareness following ABI is presented. Emphasis is placed on terminology, theories, measurement, treatment, and the relationship between impaired awareness and emotional distress. It was established that the relationship between impaired awareness and aspects of neuropsychological and mood functioning is still unclear. In addition, relatively few empirical studies have investigated treatment techniques for impaired awareness.

This study investigated the association between impaired awareness and executive functioning, and the relationship between impaired awareness and emotional distress with a sample of 30 adults with ABI. A sub-sample of 17 individuals with impaired awareness participated in an intervention where they received feedback of their brain scan findings. The main finding of the study was that measures of impaired awareness and emotional distress decreased following the feedback intervention. No evidence of a statistically significant relationship between impaired awareness and mood, or impaired awareness and executive functioning was found. There was a trend towards poor planning ability being related to unrealistic goal setting. Recommendations for further research in this area of neuropsychology and neurorehabilitation are made.

ACKNOWLEDGEMENTS

I wish to thank the following persons for making this study possible:

1. Dr Rudi Coetzer, for making this journey a reality and supporting me in countless ways
2. The participants, who gave of their time unselfishly
3. Conwy and Denbighshire NHS Trust, for providing the funding which enabled me to complete the D. Clin. Psy. Degree
4. Dr Isabel Hargreaves, for the opportunity to undertake the course
5. Dr Frances Vaughan, for her support and encouragement

To the one that got away from us

SECTION 1. ETHICS PROPOSAL

Awdurdod Iechyd Gogledd Cymru
North Wales Health Authority
Research Ethics Committee
(West, Central & East sub-committees)

Important guidance notes accompany this form. Applicants MUST refer to the corresponding note before answering each question. Incomplete forms cannot be accepted.

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1. Title of project: Standardised Clinician Feedback of Brain Scan Findings - Effect on Impaired Self-Awareness and Mood in Acquired Brain Injury

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2. Principal investigator:

name : Mr. C.B. Roberts

address : North Wales Brain Injury Service
Colwyn Bay Community Hospital
Hesketh Road
Colwyn Bay
LL29 8AY

job title: Clinical Psychologist

telephone number: 01492-807521

3. Other investigators:

- Dr. B.R Coetzer, Consultant Neuropsychologist and Head of Service, North Wales Brain Injury Service (contact address and telephone number same as for principle investigator)
- Prof. R. Rafal, Consultant Neurologist, North Wales Brain Injury Service, Professor of Neurosciences and Neuropsychology, University of Wales, Bangor (contact address and telephone number same as for principle investigator)

Please direct all correspondence regarding this application to the principle investigator

4. Who is initiating this project?
Mr. C.B. Roberts, as part of the qualification, Doctorate in Clinical Psychology, University of Wales, Bangor

Academic Supervisor: Dr B.R. Coetzer

5. Where will the research take place?
North Wales Brain Injury Service, Colwyn Bay Hospital

6. Objectives of the project:
The primary aim of the proposed study will be to evaluate the outcome of feedback of brain scan data on self-awareness and mood in a group of individuals who have sustained an acquired brain injury. Neuropsychological data (general intellectual functioning and executive functioning) will also be collected. The secondary aim of the proposed study will be to ascertain if individuals who benefited from the feedback through increased self-awareness differ from individuals who did not benefit in terms of neuropsychological test scores.

7. Scientific background to the project:

Acquired brain injury from causes such as trauma, stroke, tumour, anoxia, and infection can result in significant physical, cognitive, and behavioural difficulties. Such injury can also result in a failure to recognise and appreciate the nature and the consequences of these difficulties (Sherer, Oden, Bergloff, Levin & High, 1998). Individuals with these difficulties are said to have impaired self-awareness or anosognosia. Impaired self-awareness can present as complete lack of awareness of the injury or can be as subtle as a failure to notice inappropriate social behaviour. There appears to be general agreement that impaired self-awareness significantly complicates the rehabilitation process (Sherer, Boake, et al., 1998). This can hamper an individual's ability to benefit from treatment, and to make a successful return to independent living (Port, Willmott, & Charlton, 2002). In order for neurorehabilitation to be effective it is necessary that impaired self-awareness be considered and addressed in the treatment process.

Various approaches have been utilised in the treatment of impaired awareness. These have included education, direct therapist feedback, and experiential therapy (Sherer, Oden, et al., 1998). To date no study has investigated the utility of reviewing brain scan data to improve self-awareness levels. This study will investigate this by employing a standardised feedback process. The appeal of this approach lies in its ability to provide a concrete and visual medium to explain the clinical implications of brain injury. This approach may be useful for individuals with brain injury as they often have difficulty understanding abstract concepts.

Depression has also been recognised as a common and important consequence of acquired brain injury (Stonnington, 2001). Self-awareness has been related to depression as a risk factor and as a protective factor by differing authors. The view of impaired self-awareness as a protective factor holds that limited self-awareness protects the individual against the reality of the losses he or she has experienced, thus preventing depression. This view does not appear to have unequivocal support in the research literature. For example it has been shown that following a cerebrovascular accident (CVA) anosognostic patients are no more or less depressed than non-anosognostic CVA patients. (Starkstein, Fedoroff, Price, Leiguarada & Robinson, 1992).

Evidence suggests that self-awareness difficulties may act as a risk factor for depression (Prigatano, 1997). In a review of the literature Ownsworth and Oei (1998) concluded that an individual with a brain injury is most susceptible to depression when he or she has poor awareness of his or her deficits. Individuals who show impaired self-awareness may set unrealistic goals for themselves by attempting to return to their pre-morbid lifestyle. They may experience frustrations, lose friends, and employment and as a result of this become depressed. Improving self-awareness may therefore reduce the perplexity they face over their situation, give them a better appreciation of their problems, and allow them to set realistic goals. This study will investigate whether there is a change in the mood status of research participants following the intervention aimed at increasing levels of self-awareness.

A number of studies have investigated the correlation between self-awareness and performance on neuropsychological measures. Many of these studies have focussed on measuring executive functions such as planning, concept formation, cognitive switching and perseveration. The rationale for this draws on theories linking disorders of self-awareness with frontal system dysfunction (Prigatano, 1991). To date the results have been equivocal with some studies demonstrating a correlation between self-awareness levels and neuropsychological test scores (Ownsworth, McFarland, & Young, 2002; Bogod, Mateer, &

MacDonald, 2003) and others failing to find a correlation (Prigatano & Leathem, 1993).

There have been no studies to date that have investigated whether an individual's neuropsychological status is related to his or her ability to benefit from an intervention designed to address impaired self-awareness. The present study will investigate whether individuals who benefit from the intervention differ from those who do not by examining whether differences exist in general intellectual functioning, memory functioning and executive functioning.

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8. Study design:

Procedure

Participants will be current patients of the North Wales Brain Injury Service. Senior clinicians will be asked to refer appropriate patients for participation. Participants will then be screened according to the inclusion criteria. This will include an assessment of self-awareness. Patients who demonstrate impaired self-awareness will be included in the study. Inclusion in the study furthermore will also depend on the availability of a brain scan (CT/MRI) that indicates a positive finding (e.g. cerebral haemorrhage or contusion).

The next phase will include administering the neuropsychological tests and clinical measures of mood.

Participants and their carers will then be scheduled in to see a Consultant Neurologist (Co-investigator: Prof. R. Rafal) approximately two weeks after administering the psychological tests. The clinical measures of mood will be re-administered just prior to the consultation. During the consultation the Neurologist will conduct a review of the available brain scan with the participant according to the following protocol.

a. Neurologist will explain rationale and methodology of brain scanning
b. Neurologist will point out the gross landmarks of the brain
c. Neurologist will explain pathological findings in lay terms
d. Neurologist will explain possible neurobehavioural consequences
e. Neurologist will discuss possible treatment considerations
f. Opportunity will be given for participant to discuss findings/ask questions

The self-awareness measures and the clinical measures of mood will be repeated directly after the consultation.

The self-awareness measures and mood measures will then be repeated 1 - 2 weeks after the consultation. During this consultation participants will be asked to complete a brief questionnaire to determine if they found the feedback consultation helpful. This questionnaire relates to Prof. Rafal's clinical audit requirements.

Measures

The following measures/tests/interview will be used as described in the complete protocol:

Self-awareness:

Awareness Questionnaire (AQ; Sherer, Bergloff, Boake, High, & Levin, 1998)
The AQ measures self-awareness by asking patient, family member/significant other, and/or clinician to separately rate the patient's abilities to perform various tasks after the injury as compared to before the injury. These are rated on a five-point scale ranging from "much worse" to "much better". The difference between the patient's ratings and that of the family member/significant other and/or clinician is considered to be a measure of impairment in self-awareness.

The participant and a family member/significant other will be required to complete the applicable version of the AQ. This will allow for the difference score, indicating degree of self-awareness to be calculated.

Self-Awareness of Deficits Interview (SADI; Fleming, Strong, & Ashton, 1996)
The SADI is a structured interview in which the examiner asks the individual specific questions relating to self-awareness. The scale allows questioning in three areas: (1) self-awareness of deficit, (2) self-awareness of functional implications of deficit, and (3) ability to set realistic goals. The interviewer then scores according to a pre-established rating scale to determine level of self-awareness.

Mood:

Beck Depression Inventory - Second Edition (BDI-II; Beck, Steer, & Brown, 1996)
The BDI-II is a 21-item self-report instrument for measuring the severity of depression in adults. The BDI-II was developed for the assessment of symptoms corresponding to criteria for diagnosing depressive disorder listed in the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (1994). The BDI has been utilised and researched for use in an acquired brain injury population (Sliwinski, Gordon, Bogdany, 1998; Glenn, O'Neil-Pirozzi, Goldstein, Burke, & Jacob, 2001)

The Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994)
The HADS was designed as a brief measure of anxiety and depression. It consists of two sub-scales, one measuring anxiety and one measuring depression, which are scored separately. The HADS is a present-state instrument designed for use in medical hospital departments. It is applicable for repeated usage and may be administered at weekly intervals.

Neuropsychological tests:

Weschler Abbreviated Scale of Intelligence (WASI; Psychological Corporation, 1999)
The WASI is a brief, reliable means of assessing general intellectual functioning in clinical and research settings. It consists of 4 sub-tests (Vocabulary, Similarities, Block Design, and Matrix Reasoning) and provides a measure of general, performance and verbal intelligence.

National Adult Reading Test (NART; Nelson & Willison, 1991)
The NART is a validated measure that provides an estimate of pre-morbid intellectual ability.

Wisconsin Card Sorting Test - Computerised Version (WCST; Heaton, Chelune, Talley, Kay, & Curtiss, 1993)
The WCST provides a measure of flexible thinking and abstract reasoning ability. It is considered to be the 'gold standard' test of executive functioning and has been widely validated in lesioning and neuro-imaging studies (Royall et al., 2002). The WCST provides measures of perseveration, conceptual level thinking, learning, and cognitive set maintenance.

Tower Test - (Delis, Kaplan, & Kramer, 2001)
The Tower Test is a stand-alone sub-test of the Delis Kaplan Executive Function System (DKEFS). The Tower Test measures several key executive functions including spatial planning, rule learning, inhibition of impulsive responding, inhibition of perseverative responding, and establishing and maintaining the instructional set.

Logical Memory - Weschler Memory Scales 3rd Edition (WMS-III; Psychological Corporation, 1998)
Logical Memory is a sub-test of the WMS. Logical memory consists of two parts and measures immediate and delayed verbal memory.

Faces - WMS-III (Psychological Corporation, 1998)
Faces is a visual memory sub-test of the WMS-III. This sub-test uses a recognition paradigm to measure immediate and delayed memory.

Data Analysis

The primary aim of the study will be to evaluate the effectiveness of the intervention in increasing self-awareness and to assess mood-state before and after the intervention. The secondary aim will be to determine if change following the intervention is correlated with neuropsychological measures. The study design can be considered a Within Subjects Design, with repeated measures, correlational study. The data will be analysed with SPSS and appropriate statistical analyses performed.

9. Have you had statistical advice in preparing your protocol? If so, from whom?
Yes, Dr Richard Hastings, Research Director, North Wales Clinical Psychology Programme, School of Psychology, University of Wales, Bangor. Advice suggested that for an effect size of .8 a sample size of 20-24 would be required.

10. What are the possible benefits and hazards of this research?

The specific benefits of the research for participants may include gaining knowledge about their acquired brain injury thus helping them to direct their own rehabilitation efforts. The research may consequently assist participants to achieve rehabilitation goals.

No hazards are anticipated. The research will not include aspects of clinical practice not already undertaken at the North Wales Brain Injury Service. Participants will however be monitored closely. Counselling will be offered in the event of any participant experiencing psychological difficulties.

11. Participants :

11.1 type of participant
Selection criteria:

- Persons with an acquired brain injury (e.g. traumatic brain injury cerebro-vascular accident, cerebral infection, anoxia)
- Presence of a positive findings on brain imaging (CT or MRI)
- Established self-awareness deficit (as determined by AQ and SADI)
- At least 6 months since injury
- Absence of pre-morbid learning disability
- Absence of substance misuse that requires current active treatment
- Absence of severe psychiatric illness

11.2 method of recruitment
Participants will be recruited from North Wales Brain Injury Service active Caseload - both current and newly referred patients. Senior Clinicians will be invited to refer patients to the study

11.3 numbers of participants involved
The study aims to recruit 20-24 participants to the study

11.4 age groups involved
Over 18 years of age

11.5 do you intend to recruit 'vulnerable' participants?
(if yes, please explain)
Due to the nature of acquired brain injury, some participants may be viewed as vulnerable. Vulnerable in this sense refers to cognitive difficulties that may hamper efficient mental functioning. All efforts will be made to ensure that the participants' cognitive difficulties do not disadvantage them in making an informed consent. No-one deemed vulnerable by treating clinicians will be recruited for this study.

11.6 will consent be written or oral, or both?
Both

11.7 are participants competent to give informed consent?
Yes. Only patients who are competent to provide informed consent will be approached to participate in the research

11.8 how much time will be allowed between explaining the research and requesting consent?
One week

11.9 who will witness the consent?
The investigator and the participant's carer

11.10 will individuals already participating in other research be excluded?
Yes, if they are involved in an intervention study

11.11 will participants be inconvenienced in any way as a result of taking part in the study?
Participants will be required to make a journey to the North Wales Brain Injury Service. They will be asked to participate in the psychometric assessment, measure collection, and an intervention session.

11.12 will participants receive payment or reward for taking part? If so, please give details.
No

12. <u>Disclosure of payment or reward to investigators :</u>

12.1 will any payment be made to the investigators or department/ unit in respect of this trial?

No

12.2 if yes, will the payment be a block grant, or will it be based on the number of participants recruited ?
N/A

12.3 if a block grant, please state amount awarded and explain how monies received will be spent.

N/A

12.4 if payment is based on number of participants recruited, please state total sum payable per capita, and number of participants agreed.

N/A

12.5 will participants be informed if the investigator / department is receiving payment, and if so, will they be told the name of the sponsor?

N/A

12.6 do any of the investigators have a personal involvement in the sponsoring company? If so, please give details.

N/A

13. <u>Consent of others clinically involved :</u>

13.1 will the participant's GP be informed of their involvement in the project?

Yes

13.2 will the consent of others clinically involved be obtained?

Consent to conduct the research has been given by the Head of Service for the North Wales Brain Injury Service

14. <u>Resource / service implications :</u>

14.1 will your research have resource / service implications for the NHS?

No. Additional financial costs (e.g. costs of test material) will be covered by the North Wales Clinical Psychology Programme

14.2 if yes, please indicate the applicable areas

14.3 have you discussed any additional workload and / or financial consequences of your project with the departments and budget holders concerned?

Yes

15. Extra substances to be given to the participants :

15.1 additional drugs
N/A

15.2 dosage form and presentation of these drugs
N/A

15.3 route of administration of these drugs
N/A

15.4 amount
N/A

15.5 frequency
N/A

15.6 desired effect
N/A

15.7 possible side effects
N/A

15.8 precautions
N/A

15.9 does the study medicine to be used have a marketing authorisation (product licence)?
N/A

15.10 if yes, will the medicine be used in accordance with, and for the indications specified in, the licence?
N/A

15.11 if the medicine does not have a product licence, or it will not be used in accordance with a product licence, does it have a clinical trial certificate (CTC) or an exemption under either the CTX or DDX schemes?
N/A

15.12 is the clinical trial randomisation code to be held by pharmacy?

N/A

15.13 what procedures will be followed if the codes are to be broken in an emergency?

N/A

15.14 please give full details of any other extra (non-drug) substances to be given to participants

N/A

16. Extra interventions :

16.1 will the project involve any extra venous samples? If so, please give details.

No

16.2 will the project involve any extra arterial samples? If so, please give details.

No

16.3 will the research involve extra x-rays, radiation, ultrasonics, scanning, ecg or other tests? If so, please give details.

No

16.4 will the research involve extra biopsies? If so, please give details.

No

16.5 will the research involve extra local or general anaesthesia? If so, please give details.

No

16.6 will the research involve any other extra invasive procedures such as cannulae, probes, catheters, internal examinations, endoscopies or lumbar punctures? If so, please give details.

No

16.7 will the research involve extra psychological tests? If so, please give details.

No

16.8 will the research involve extra questionnaires? If so, please give details.

Yes. Participants will be asked to indicate via a questionnaire whether they perceived the feedback session as beneficial and also invited to provide any comments. This questionnaire is attached.

16.9 will the research involve any other extra procedures not mentioned above, such as those using heat or electricity etc.? If so, please give details.

No

16.10 will the research necessitate any treatments or procedures being withheld which would otherwise be administered? If so, please give details.

No

17. Ionising radiation :

17.1 will subjects be exposed to ionising radiation as part of this study?

No

17.2 if so, specify the procedures which will be performed, and state the total effective dose in msv which will be received.

N/A

18. What problems may hinder successful completion of this study?

Recruitment difficulties

19. What steps will be taken to safeguard confidentiality of the research records?

Participants will be identified on the research records using an alphanumeric code rather than their names. The list of names and codes will be kept in a locked clinical records cabinet

20. Please explain any arrangements made for indemnity cover for participants.

N/A

21. Does the project comply with the requirements of the data protection act?

Yes

22. Please state the anticipated start and end dates for your study.

March 2004 - September 2005

23. Investigator's declaration :

The information provided above is to the best of my knowledge accurate. I fully understand my obligations and the rights of the participant, particularly with regard to freely given informed consent.

Signed: Print name: Date:

24. Head of Department's endorsement :

I hereby endorse this research proposal with my approval.

Signed: Print name: Date:

Appendix A. Letter to Ethics Committee

2nd October 2004

Ms E Thomas

North East Wales LREC

Medical Support Service

The Old Rec. Hall

Wrexham Maelor Hospital

Croesnewydd Road

Wrexham

LL13 7TD

Dear Ms Thomas

Re: Study Title - Standardised Clinician Feedback of Brain Scan Findings: Effect on Impaired Self-Awareness and Mood in Acquired Brain Injury

Further to your letter dated 15 March 2004. I am writing to inform you of a minor protocol change to the above research project. I will be substituting one psychological test (National Adult Reading Test) with another (Verbal Fluency Test).

I hope this is satisfactory.

Yours sincerely

Craig B. Roberts

Clinical Psychologist

North Wales Brain Injury Service

Appendix B. Participant information sheets

PARTICIPANT INFORMATION SHEET

Study: Feedback of brain scan findings: Effect on understanding and mood in acquired brain injury

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

What is the purpose of this study?

This research aims to find out if feeding back the results of brain scan findings (looking at the brain scan and discussing the results) helps a person in understanding the nature and effects of their brain injury. Often after a person has sustained a brain injury a radiological picture is taken of the brain. These are usually CT scans or MRI scans and can show us where the brain has been injured. In addition we want to know if feeding back the results of a brain scan has any effect on a person's mood. By mood we mean the way you feel. We also want to find out if certain people with a brain injury benefit more from the brain scan feedback process. In order to find this out we will do some psychological tests before giving the feedback.

Why have I been chosen?

You have been asked to take part because you have had an acquired brain injury (for example a traumatic brain injury, stroke, encephalitis, anoxia) and are currently an active patient of the North Wales Brain Injury Service. We will be asking about 20 other people to take part who are in similar circumstances to you.

Do I have to take part?

It is up to you to decide whether or not you wish to take part. If you do take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive from the North Wales Brain Injury Service now or in the future.

What will happen to me if I take part?

If you agree to take part you will initially come to the Brain Injury Service for an appointment where you will have a one-to-one appointment with a researcher. This would be similar to appointments you have at the Brain Injury Service. During this appointment you and a close family member, friend, or carer will be asked to complete a questionnaire that asks you about your brain injury. In addition you will be asked to take part in an interview in which you will be asked about your brain injury and your understanding of it.

We will then analyse the results of the questionnaire and interview. If we think the results indicate that you could benefit from our project we will invite you back for a further appointment to complete six neuropsychological tests and two questionnaires about your mood. Each of these tests should take no longer than 5 to 10 minutes to complete.

This will be followed by the brain scan feedback session. During this appointment you will meet with a Consultant Neurologist who will explain to you about brain scanning in general, the results of any brain scans you have had done, and what the possible consequences of the findings are. You will also be given an opportunity to discuss anything in further detail.

You will then be asked to attend a final appointment. During this appointment you will be asked to repeat some of the questionnaires you have previously completed. In addition you will be given an opportunity to tell us, via a questionnaire if you found the feedback of brain scan findings helpful or not.

What do I have to do?

You will be asked to visit the Brain Injury Service. If this is inconvenient for you we will try to schedule some of the appointments nearer to your home. The appointment with the Neurologist to review your brain scans will however need to be held at the Brain Injury Service.

What is the procedure being tested?

The procedure being tested is a standardised feedback review of brain scan findings. It consists of the following steps:

1. Explaining to you what is brain scanning
2. Showing you the main areas of the brain on your scans
3. Showing you on the scans where your brain was affected by the injury
4. Explaining to you the possible consequences of the brain scan findings
5. Discussing with you possible treatment options
6. Giving you an opportunity to discuss the findings and ask questions

What are the alternatives?

The alternative is to continue with the standard treatment you already receive at the Brain Injury Service. Your current treatment will not be affected in any way by agreeing or not agreeing to take part in this research.

What are the side effects of taking part?

The research should not cause any side effects or discomfort.

What are the possible disadvantages of taking part?

Occasionally people may become upset and feel low when they have to talk about their brain injury and how it affects them. If this happens you will be given the chance to talk this through with one of the researchers or your clinicians at the Brain Injury Service. Counselling will also be available through the Service.

What are the possible benefits of taking part?

You may benefit from this research by gaining a better understanding of you injury and how it affects you. Previous research has shown that rehabilitation works better when a person understands the nature and consequences of their brain injury.

What if something goes wrong?

If you were to agree to take part in this research and subsequently have any concerns about any aspect of the research, you can approach the researcher Craig Roberts directly to discuss these. The names of persons to direct complaints to are also provided at the end of this leaflet. The usual NHS complaints procedures are also available to all research participants.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that leaves the Brain Injury Service will have your name address removed so that you cannot be recognised from it.

Who is organising and funding the research?

This study is being organised by Craig Roberts as part of his degree, Doctor of Clinical Psychology at the University of Wales, Bangor. The North Wales Clinical Psychology Program will meet additional costs of the research.

What will happen to the results of the research study?

The results of this study will tell us whether reviewing brain scan findings is a useful procedure and if so for whom it might be useful. The results of this study will be written up in Craig Roberts's dissertation for his degree. The results may also be included in a published research report. No participant will be identified in the dissertation or report.

Who has reviewed the study?

The North Wales Health Authority East Ethics Committee and the University of Bangor, School of Psychology's Research Ethics Committee have approved the study.

Contact for further information:

Craig Roberts

North Wales Brain Injury Service

Colwyn Bay Hospital

Hesketh Road

Colwyn Bay.

Telephone: 01492 – 807521

If you take part in this study you will be given a copy of the Information Sheet and a signed consent form to keep.

In case of any complaints concerning the conduct of research, these should be addressed to:

Mrs Lesley Ross

Patient Services

Clinical Support Unit

HM Stanley Hospital

St Asaph

LL17 0RS

Or

Professor Fergus Lowe

Head of School of Psychology

University of Wales – Bangor

Bangor

LL57 2DG

Thank you for reading this and for considering taking part in this study

TAFLEN WYBODAETH I GLEIFION

Astudiaeth: Atborth o ddarganfyddiadau sgan yr ymennydd: Effaith ar ddealltwriaeth a hwyliau mewn anaf caffaeledig i'r ymennydd

Fe'ch gwahoddir i gymryd rhan mewn astudiaeth ymchwil. Cyn i chi benderfynu, mae'n bwysig i chi ddeall pam bod yr ymchwil yn cael ei wneud a beth mae'n gynnwys. Cymerwch eich amser i ddarllen y wybodaeth hon yn ofalus a thrafodwch gyda ffrindiau, perthnasau a'ch meddyg teulu os ydych yn dymuno. Os oes unrhyw beth yn aneglur neu os hoffech fwy o wybodaeth, mae croeso i chi ofyn i ni. Cymerwch eich amser i benderfynu a ydych am gymryd rhan neu beidio.

Diolch am ddarllen y daflen wybodaeth hon.

Beth yw pwrpas yr astudiaeth?

Nod yr ymchwil hon yw darganfod a yw rhoi canlyniadau darganfyddiadau sgan ymennydd (edrych ar sgan ymennydd a thrafod y canlyniadau) yn ôl yn helpu unigolyn ddeall natur ac effeithiau ei anaf ymennydd. Yn aml ar ôl i rywun anafu'r ymennydd, bydd llun radiolegol yn cael ei gymryd o'r ymennydd. Fel arfer sganiau CT neu MRI yw'r rhain ac maent yn gallu dangos i ni lle anafwyd yr ymennydd. Yn ogystal â hyn, rydym am gael gwybod a yw rhoi canlyniadau sgan ymennydd yn cael effaith ar hwyliau unigolyn. Rydym yn golygu sut mae rhywun yn teimlo wrth ddweud hwyliau. Rydym hefyd am gael gwybod a yw rhai pobl gydag anafiad ymennydd yn cael budd o'r broses atborth sgan ymennydd. Er mwyn darganfod hyn, byddwn yn gwneud profion seicolegol cyn rhoi yr atborth.

Pam rydw i wedi cael fy newis?

Gofynnwyd i chi gymryd rhan oherwydd eich bod wedi cael anaf caffaeledig i'r ymennydd (e.e. anaf trawmatig i'r ymennydd, strôc, enseffalitis, anocsia) ac rydych ar hyn o bryd yn glaf gweithredol Gwasanaeth Anaf i'r Ymennydd Gogledd Cymru. Byddwn yn gofyn i oddeutu 20 o bobl eraill sydd mewn sefyllfa tebyg i chi gymryd rhan.

Oes raid i mi gymryd rhan?

Dylech chi benderfynu a ydych am gymryd rhan neu beidio. Os byddwch yn cymryd rhan, byddwch yn cael y daflen wybodaeth hon i'w chadw a gofynnir i chi lofnodi ffurflen gydsynio. Os byddwch yn penderfynu cymryd rhan, mae'r hawl gennych i dynnu'n ôl unrhyw bryd a heb roi rheswm. Ni fydd hyn yn effeithio ar safon y gofal gan Wasanaeth Anaf i'r Ymenydd Gogledd Cymru, nawr ac i'r dyfodol.

Beth fydd yn digwydd i mi os byddaf yn cymryd rhan?

Os byddwch yn penderfynu cymryd rhan, byddwch yn dod i'r Gwasanaeth Anaf i'r Ymennydd am apwyntiad a byddwch yn cael apwyntiad un-wrth-un gydag ymchwilydd. Byddai hyn yn debyg i apwyntiadau rydych yn eu cael yn y Gwasanaeth Anaf i'r Ymennydd. Yn ystod yr apwyntiad, gofynnir i chi, aelod agos o'r teulu, ffrind neu ofalydd gwblhau holiadur sy'n eich holi ynghylch eich anafiad i'r ymennydd. Yn ogystal â hyn, gofynnir i chi gymryd rhan mewn cyfweliad a byddwch yn cael eich holi ynghylch eich anafiad i'r ymennydd a'r hyn rydych yn ei ddeall amdano.

Wedyn, byddwn yn dadansoddi canlyniadau'r holiadur a'r cyfweliad. Os byddwn yn credu bod y canlyniadau yn nodi y gallech gael budd o'n prosiect, byddwn yn eich gwahodd yn ôl am apwyntiad pellach i gwblhau chwe phrawf niwroseicolegol a dau holiadur ynghylch eich hwyliau. Ni fydd unrhyw un o'r profion yn cymryd mwy na 5-10 munud i'w cwblhau.

Dilynnir hyn gyda sesiwn atborth sgan ymennydd. Yn ystod yr apwyntiad, byddwch yn cyfarfod â Niwrolegydd Ymgynghorol a fydd yn esbono sganio ymennydd yn gyffredinol i chi, canlyniadau unrhyw sganiau ymennydd a wnaed i chi a beth yw'r canlyniadau posibl o'r darganfyddiadau. Byddwch hefyd yn cael cyfle i drafod unrhyw beth ymhellach.

Gofynnir i chi wedyn fynychu apwyntiad olaf. Yn ystod yr apwyntiad gofynnir i chi ailwneud rhai o'r holiaduron a gwblhawyd o'r blaen. Yn ogystal â hyn, byddwch yn cael y cyfle i ddweud wrthym, drwy gyfrwng holiadur a fu'r atborth o'r darganfyddiadau sgan ymennydd o gymorth i chi neu beidio.

Beth y mae'n rhaid i mi ei wneud?

Gofynnir i chi ymweld â'r Gwasanaeth Anaf i'r Ymennydd. Os nad yw hyn yn gyfleus i chi, byddwn yn ceisio trefnu rhai o'r apwyntiadau yn agosach i'ch cartref. Bydd raid i'r apwyntiad gyda'r Niwrolegydd fod yn y Gwasanaeth Anaf i'r Ymennydd.

Pa weithdrefn sy'n cael ei brofi?

Mae'r weithdrefn sy'n cael ei phrofi yn adolygiad atborth safonol o ddarganfyddiadau sgan ymennydd. Mae'n cynnwys y camau canlynol:

1. Esbonio beth yw sganio'r ymennydd i chi
2. Dangos i chi prif fannau eich ymennydd ar eich sganiau
3. Dangosi i chi ar y sganiau lle a effeithiwyd gan yr anaf ar eich ymennydd
4. Esbonio i chi'r canlyniadau posibl o ddarganfyddiadau'r sgan ymennydd
5. Trafod gyda chi y dewisiadau triniaethau posibl
6. Rhoi cyfle i chi drafod y darganfyddiadau a gofyn cwestiynau

Beth yw'r dewisiadau eraill?

Y dewisiadau eraill yw parhau gyda'r driniaeth safonol rydych eisoes yn ei derbyn gan y Gwasanaeth Anaf i'r Ymennydd. Ni fydd y driniaeth rydych yn ei derbyn nawr yn cael ei heffeithio mewn unrhyw ffordd drwy gytuno neu anghytuno cymryd rhan yn y rhan hon o'r ymchwil.

Beth yw'r sgîl effeithiau wrth gymryd rhan?

Ni ddylai'r ymchwil achosi unrhyw sgîl effeithiau neu anesmwythdod.

Beth yw'r anfanteision posibl o gymryd rhan?

Yn achlysurol bydd rhai pobl yn teimlo'n ofidus ac isel pan mae'n rhaid iddynt siarad am eu anaf ymennydd a sut mae'n effeithio arnynt. Os bydd hyn yn digwydd i chi, rhoddir y cyfle i chi siarad am hyn gydag un o'r ymchwilwyr neu eich clinigwr yn y Gwasanaeth Anaf i'r Ymennydd. Bydd gwasanaeth cwnsela ar gael drwy'r gwasanaeth.

Beth yw'r buddion posibl o gymryd rhan?

Mae'n bosibl y byddwch yn cael budd o'r ymchwil hwn drwy ddeall eich anaf a sut mae'n effeithio arnoch yn well. Mae ymchwil blaenorol wedi dangos bod adsefydlu'n gweithio'n well pan fydd yr unigolyn yn deall natur a chanlyniadau eu hanaf ymennydd.

Beth os aiff rhywbeth o'i le?

Os byddwch yn cytuno i gymryd rhan yn yr ymchwil hwn ac o ganlyniad, mae gennych bryderon ynghylch unrhyw agwedd o'r ymchwil, cewch gysylltu â'r ymchwilydd Craig Roberts yn uniongyrchol i drafod y materion. Nodir enwau'r unigolion y dylid cyfeirio cwynion atynt hefyd ar ddiwedd y daflen hon. Mae'r weithdrefn gwyno GIG arferol ar gael hefyd i bawb sy'n cymryd rhan yn yr ymchwiliad.

A fydd fy rhan yn yr astudiaeth hon yn cael ei chadw'n gyfrinachol?

Bydd yr holl wybodaeth a gasglwyd amdanoch chi yn ystod yr ymchwil yn cael ei chadw'n hollol gyfrinachol. Bydd unrhyw wybodaeth sy'n gadael y Gwasanaeth Anaf i'r Ymennydd yn mynd heb eich enw a'ch cyfeiriad, fel na eillir eich adnabodd oddi wrtho.

Pwy sy'n trefnu ac yn ariannu'r ymchwil?

Trefnwyd yr astudiaeth gan Craig Roberts fel rhan o'i radd Doethuriaeth Seicoleg Clinigol ym Mhrifysgol Cymru, Bangor. Bydd Rhaglen Seicoleg Clinigol Gogledd Cymru yn cwrdd ag unrhyw gostau ychwanegol yr ymchwil.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth ymchwil?

Bydd canlyniadau'r astudiaeth yn dweud wrthym a fu adolygu canlyniadau sgan yr ymennydd yn weithdrefn ddefnyddiol ac os yw, pwy fyddai'n cael budd ohono. Bydd canlyniadau'r astudiaeth yn cael eu hysgrifennu gan Craig Roberts yn ei draethawd gradd. Mae'n bosibl bydd y canlyniadau'n cael eu cynnwys mewn adroddiad ymchwil a gaiff ei gyhoeddi. Ni fydd modd adnabod unrhyw un a gymerodd ran yn y traethawd na'r adroddiad.

Pwy sydd wedi adolygu'r astudiaeth?

Mae Pwyllgor Moeseg Dwyrain Awdurdod Iechyd Gogledd Cymru a Phwyllgor Moeseg Adran Ymchwil Seicoleg, Prifysgol Cymru, Bangor, wedi cymeradwyo'r astudiaeth.

Cyswllt am Wybodaeth Bellach:

Craig Roberts

Gwasanaeth Anaf i'r Ymennydd Gogledd Cymru

Ysbyty Bae Colwyn

Ffordd Hesketh

Bae Colwyn

Ffôn: 01492 – 807521

Os byddwch yn cymryd rhan yn yr astudiaeth, rhoddir copi o'r daflen wybodaeth hon i chi a ffurflen gydsynio wedi'i llofnodi i chi eu cadw.

Os bydd unrhyw gwynion ynghych yr ymchwil, dylid eu cyfeirio at:

Mr Gren Kershaw

Prif Weithredwr

Ymddiriedolaeth GIG Siroedd Conwy a Dinbych

Ysbyty Glan Clwyd

Bodelwyddan

Y Rhyl LL18 5UJ

neu

Yr Athro Fergus Lowe

Pennaeth Adran Seicoleg

Prifysgol Cymru, Bangor

Bangor LL57 2DG

Diolch i chi am ddarllen y daflen hon ac ystyried cymryd rhan

Appendix C. Consent form for participants

Research Consent Form

Title of Study: Standardised clinician feedback of brain scan findings: Effect on self-awareness and mood in acquired brain injury.

(The patient should complete the whole of this sheet himself/herself)

(Please cross out as necessary)

Have you read the Patient Information Sheet? .. .. .. YES/NO

Have you had the opportunity to ask questions and discuss this study? YES/NO

Have you received satisfactory answers to all of your questions? .. YES/NO

Have you received enough information about the study? .. .. YES/NO

Do you understand that you are free to withdraw from the study:

At any time

Without having to give a reason

And without affecting you future medical/psychological care YES/NO

Do you agree to take part in this study? .. .. YES/NO

Signed:_____ Date:_____

Name (in block letters) _____

Signature of witness: _____

<u>Ffurflen Gydsynio i Ymchwil</u>

Teitl yr Astudiaeth: Atborth safonol clinigwr o ddarganfyddiadau sgan ymennydd: Effaith ar hunanymwybyddiaeth a hwyliau mewn anaf caffaeledig i'r ymennydd.

(Dylai'r claf gwblhau'r daflen hon i gyd ar ei ben/phen ei hun.)

(Dilëer lle bo angen)

Ydych chi wedi darllen y Daflen Wybodaeth i Gleifion?	YDW/NAC YDW
Ydych chi wedi cael cyfle i ofyn cwestiynau a thrafod yr astudiaeth?	YDW/NAC YDW
Ydych chi wedi cael atebion boddhaol i'ch holl gwestiynau?	YDW/NAC YDW
Ydych chi wedi derbyn digon o wybodaeth ynghylch yr astudiaeth?	YDW/NAC YDW

Ydych chi'n deall eich bod â hawl i dynnu allan o'r astudiaeth:

Unrhyw amser

Heb roi rheswm

A heb effeithio ar eich gofal meddygol/seicolegol yn y dyfodol	YDW/NAC YDW
Ydych chi'n cytuno cymryd rhan yn yr astudiaeth hon?	**YDW/NAC YDW**

Llofnod:_____ Dyddiad:_____

Enw (LLYTHRENNAU BRAS) _____

Llofnod y Tyst: _____

Appendix D. The Awareness Questionnaire

Awareness Questionnaire
Patient Form

Name:_____ Patient #:_____ Date:_____

1	2	3	4	5
much worse	a little worse	about the same	a little better	much better

___ 1. How good is your ability to live independently now as compared to before your injury?

___ 2. How good is your ability to manage your money now as compared to before your injury?

___ 3. How well do you get along with people now as compared to before your injury?

___ 4. How well can you do on tests that measure thinking and memory skills now as compared to before your injury?

___ 5. How well can you do the things you want to do in life now as compared to before your injury?

___ 6. How well are you able to see now as compared to before your injury?

___ 7. How well can you hear now as compared to before your injury?

___ 8. How well can you move your arms and legs now as compared to before your injury?

___ 9. How good is your coordination now as compared to before your injury?

___ 10. How good are you at keeping up with the time and date and where you are now as compared to before your injury?

___ 11. How well can you concentrate now as compared to before your injury?

___ 12. How well can you express your thoughts to others now as compared to before your injury?

____ 13. How good is your memory for recent events now as compared to before your injury?

1	2	3	4	5
much worse	a little worse	about the same	a little better	much better

____ 14. How good are you at planning things now as compared to before your injury?

____ 15. How well organized are you now as compared to before your injury?

____ 16. How well can you keep your feelings in control now as compared to before your injury?

____ 17. How well adjusted emotionally are you now as compared to before your injury?

Awareness Questionnaire
Family/Significant Other Form

Name:_____ Relationship to patient:_____

Patient:_____ Patient #_____ Date:_____

1	2	3	4	5
much worse	a little worse	about the same	a little better	much better

___ 1. How good is the patient's ability to live independently now as compared to before his/her injury?

___ 2. How good is the patient's ability to manage his/her money now as compared to before his/her injury?

___ 3. How well does the patient get along with people now as compared to before his/her injury?

___ 4. How well can the patient do on tests that measure thinking and memory skills now as compared to before his/her injury?

___ 5. How well can the patient do the things he/she wants to do in life now as compared to before his/her injury?

___ 6. How well is the patient able to see now as compared to before his/her injury?

___ 7. How well can the patient hear now as compared to before his/her injury?

___ 8. How well can the patient move his/her arms and legs now as compared to before his/her injury?

___ 9. How good is the patient's coordination now as compared to before his/her injury?

___ 10. How good is the patient at keeping up with the time and date and where he/she is now as compared to before his/her injury?

___ 11. How well can the patient concentrate now as compared to before his/her injury?

1	2	3	4	5
much worse	a little worse	about the same	a little better	much better

____ 12. How well can the patient express his/her thoughts to others now as compared to before his/her injury?

____ 13. How good is the patient's memory for recent events now as compared to before his/her injury?

____ 14. How good is the patient at planning things now as compared to before his/her injury?

____ 15. How well organized is the patient now as compared to before his/her injury?

____ 16. How well can the patient keep his/her feelings in control now as compared to before his/her injury?

____ 17. How well adjusted emotionally is the patient now as compared to before his/her injury?

Appendix E. The Self-Awareness of Deficits Interview

Self-Awareness of Deficits Interview

1. *Self-awareness of deficits*

Are you any different now compared to what you were like before your accident? In what way? Do you feel that anything about you, or your abilities has changed?
Do people who know you well notice that anything is different about you since the accident? What might they notice?
What do you see as your problems, if any, resulting from your injury? What is the main thing you need to work on/would like to get better?

Prompts
Physical abilities (e.g. movement of arms and legs, balance, vision, endurance)?
Memory/confusion?
Concentration?
Problem-solving, decision-making, organizing and planning things?
Controlling behaviour?
Communication?
Getting along with other people?
Has your personality changed?
Are there any other problems that I haven't mentioned?

2. *Self-awareness of functional implications of deficits*

Does your head injury have any affect on your everyday life? In what way?

Prompts
Ability to live independently?
Managing finances?
Look after family/manage home?
Driving?
Work/study?
Leisure/social life

Are there any other areas of life which you feel have changed/may change?

3. *Ability to set realistic goals*

What do you hope to achieve in the next 6 months? Do you have any goals? What are they?
In 6 months time, what do you think you will be doing? Where do you think you will be?
Do you think your head injury will still be having an affect on your life in 6 months time?
If yes: how?
If no: are you sure?

Scoring

1. Self-awareness of deficits

0 Cognitive/psychological problems (where relevant) reported by the patient/client in response to general questioning, or readily acknowledged in response to specific questioning.

1 Some cognitive/psychological problems reported, but others denied or minimized. Patient/client may have a tendency to focus on relatively minor physical changes (e.g. scars) and acknowledge cognitive/psychological problems only on specific questioning about deficits.

2 Physical deficits only acknowledged; denies, minimizes or is unsure of cognitive/psychological changes. Patient/client may recognize problems that occurred at an earlier stage but denies existence of persisting deficits, or may state that other people think there are deficits, but he/she does not think so.

3 No acknowledgement of deficits (other than obvious physical deficits) can be obtained, or patient/client will only acknowledge problems that have been imposed on him/her, e.g. not allowed to drive, not allowed to drink alcohol.

2. Self-awareness of functional implications of deficits

0 Patient/client accurately describes current functional status (in independent living, work/study, leisure, home management, driving), and specifies how his/her head injury problems limit function where relevant, and/or any compensatory measures adopted to overcome problems.

1 Some functional implications reported following questions or examples of problems in independent living, work, driving, leisure, etc. Patient/client may not be sure of other likely functional problems, e.g. is unable to say because he/she has not tried an activity yet.

2 Patient/client may acknowledge some functional implications of deficits but minimizes the importance of identified problems. Other likely functional implications may be actively denied by the patient/client.

3 Little acknowledgement of functional consequences can be obtained; the patient/client will not acknowledge problems: except that he/she is not allowed to perform certain tasks. He/she may actively ignore medical advice and may not engage in risk-taking behaviours, e.g. drinking, driving.

3. Ability to set realistic goals

0 Patient/client sets reasonably realistic goals, and (where relevant) identifies that the head injury will probably continue to have an impact on some areas of functioning, i.e. goals for the future have been modified in some way since the injury.

1 Patient/client sets goals which are somewhat unrealistic, or is unable to specify a goal, but recognizes that he/she may still have problems in some areas of funtion in the future, i.e. sees that goals for the future may need some modification, even if he/she has not yet done so.

2 Patient/client sets unrealistic goals, or is unable to specify a goal, and does not know how he/she will be functioning in 6 months time, but hopes he/she will return to pre-trauma, i.e. no modification of goals has occurred.

3 Patient/client expects without uncertainty that in 6 months time he/she will be functioning at pre-trauma level (or at a higher level).

Appendix F. The Beck Depression Inventory

Appendix G. The Hospital Anxiety and Depression Scale

Appendix H. Letter to General Practitioner

General Practitioner

Address

Postcode

Dear Doctor

Re: Patient's name, Date of birth, Address

I am writing to inform you that the above named person has volunteered to participate in a research study conducted at the North Wales Brain Injury Service. The research project will evaluate the outcome of feedback of brain scan data on self-awareness and mood in a group of individuals who have sustained an acquired brain injury. I have included a copy of the Patient Information Sheet.

The NWHA East Research Ethics Committee has approved this study.

We will inform you if your patient's participation has any unexpected adverse consequences.

Yours sincerely

Craig B. Roberts

Clinical Psychologist

North Wales Brain Injury Service

SECTION 2. LITERATURE REVIEW

To be submitted to: *Rehabilitation Psychology*

Impaired awareness following acquired brain injury: conceptual, emotional and treatment considerations

Authors:

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&

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Impaired awareness following acquired brain injury: conceptual, emotional and treatment considerations

Abstract

Objective: To present an overview of the concept of impaired awareness following acquired brain injury. *Method:* A selected overview of the literature was undertaken. The literature on impaired awareness was considered in relation to terminological aspects, theoretical models, assessment, outcome, treatment, and relationship to emotional distress. **Results:** Evidence from the literature suggests that (a) impaired awareness can be related to neurological and psychological factors; (b) empirical findings on the relationship between impaired awareness and emotional distress are mixed; and (c) few empirical treatment studies have been published for impaired awareness. *Conclusion:* Further research is needed to investigate the relationship between impaired awareness and mood. Empirical studies are required to investigate current and new treatment methods for impaired awareness.

Impaired awareness following acquired brain injury: conceptual, emotional and treatment considerations

Introduction

Acquired brain injury (ABI) may result in significant disability and has been characterised as a hidden epidemic (Flashman & McAllister, 2002). It is estimated that in the United Kingdom approximately 100 – 150 per 100, 000 of the general population are disabled as the result of a traumatic brain injury (TBI; British Society of Rehabilitation Medicine, 1988). Cerebrovascular accidents (CVA) are a further leading cause of acquired brain injury. It is reported that 1.6 – 2.0 per 1000 of the general population in the United Kingdom suffer an initial stroke each year (Bamford, Sandercock, Dennis et al., 1988). ABI is however not limited to trauma and stroke and causation extends to infectious processes, anoxia, and neoplasms. The scope of this overview will however focus primarily on TBI and CVA.

ABI often results in physical, cognitive, psychological, behavioural, and social consequences (Lezak, 1995; Prigatano, 1999a). The consequences may be evident to the affected individual and he or she may engage in treatment or seek counsel on these matters. In many instances however the changes occurring post-injury may not be obvious to the individual who has sustained an ABI. It has been reported that over 40 percent of individuals with moderate to severe TBI demonstrate problems recognising deficits that are evident to family members and clinicians (Freeland, 1996). A similar percentage of individuals who have sustained a CVA exhibit this phenomenon (Anderson & Tranel, 1989; Wagner & Cushman, 1994).

Failure to recognise impairments following ABI has been referred to by a variety of terms. These include impaired self-awareness, poor insight, denial, and anosognosia. The terminology applied to this field is used somewhat interchangeably although distinctions are made between terms depending on the theorised mechanism at work. For the purposes of this overview the term *impaired awareness* will be used to refer to reduced knowledge of any deficit following ABI.

This overview will consider contemporary concepts, paradigms, and consequences relevant to impaired awareness. One psychological consequence that has received recent attention in the literature is the association between impaired awareness and emotional distress. This overview will examine the relationship between impaired awareness and depressed mood. Given that impaired awareness may present a barrier to successful rehabilitation it is also necessary to scrutinize this within the context of possible remediation efforts. This overview will consider treatment strategies relevant to impaired awareness.

Concepts and characteristics of impaired awareness

Awareness and consciousness

In reference to self-awareness Prigatano (1997) opines that the highest of all brain functions is the 'ability to consciously process information about ourselves in a manner that reflects a relatively objective view while maintaining our unique phenomenological or subjective sense of self' (p. 301). As such, awareness is associated with consciousness and draws on knowledge of the self (Clare, 2004a). Individuals who are able to demonstrate self-awareness have the capacity to perceive

themselves in relatively objective terms within a context of personal subjectivity (Prigatano & Schacter, 1991). Deviations from this ability are referred to as impairments of awareness. Prigatano (1999b) states that individuals with poor awareness lack a subjective or phenomenological experience of impaired functioning.

Terminology considerations

McGlynn & Schacter (1989) and Prigatano & Schacter (1991) provide historic overviews on disorders of awareness. Babinski (1914) cited in McGlynn and Schacter (1989) introduced the term *anosognosia* to describe unawareness phenomena in neurological disorders. This term refers to lack of knowledge, awareness, or recognition of disease. The terms *lack of insight* and *imperception of disease* are also used to refer to diminished awareness of neuropsychological deficits and can be used interchangeably with anosognosia (McGlynn & Schacter, 1989).

Clare (2004a) describes a classification of the disturbances of awareness that includes the following: *Domain-specific unawareness* refers to impaired awareness of a specific function. *Executive unawareness* involves impaired self-regulation of behaviour. *Impaired self-awareness* concerns the deficient evaluation of impairments, an inability to translate knowledge into personal awareness, and a breakdown in relating information about the past to decisions about the future.

Kortte and Wegener (2004) provide an account of the concept of *denial*. Denial was originally introduced by Sigmund Freud and refers to a psychological defence mechanism by which the 'ego' protects the individual against unacceptable aspects of the self (Cramer, 1998). Denial was originally conceived in relation to psychiatric

disorders and is considered to be a non-neurological (psychodynamic) process. Weinstein and colleagues have most notably advocated this concept within the field of brain injury (Weinstein & Kahn, 1955; Prigatano & Weinstein, 1996). Prigatano and Klonoff (1998) propose a model to distinguish denial of illness from anosognosia. They differentiate the phenomenology of denial and anosognosia by citing the responses of individuals confronted with their impairments. For example, when told about their impairments individuals with denial may resist such claims, while those with anosognosia tend to respond with perplexity or indifference (Prigatano & Klonoff, 1998).

In general the field of brain injury has favoured neuropathological explanations over psychodynamic conceptualisations (Kortte & Wegener, 2004). Studies of impaired awareness have paid scant attention to the separation of anosognosia and denial. It is likely that research studies have included participants who exhibit anosognosia and/or denial. It is also posited that an individual can experience both anosognosia and denial simultaneously or consecutively (Boake, Freeland, Ringholz et al., 1995; Lewis, 1991).

Deficient awareness of impairments is also distinguished from *lack of concern* or *indifference* to impairments. These terms refer to the affective response exhibited by individuals who are aware of their deficits. The term *anosodiaphoria* was introduced to refer to indifference to illness and reflects a diminished emotional response to neurological impairment (McGlynn and Schacter, 1989).

Domains of impaired awareness

Self-awareness and disorders of awareness are multi-faceted concepts. It has been shown that lowered self-awareness is not restricted to the neurologically compromised and can occur in healthy individuals (Flashman & McAllister, 2002). The tendency to engage in inaccurate self-representation has been positively linked to well-being and self-esteem (Tournois, Mesnil & Kop, 2000). Flashman and McAllister (2002) formulate that self-deception is most likely to occur when there is a lack of concrete information and the motivation to deceive is high. Disorders of self-awareness occur across a range of medical conditions, psychiatric illnesses, and other neurological conditions (Kortte & Wegener, 2004; Flashman & McAllister, 2002).

Within brain injury impaired awareness can exist across a range of functional modalities. Some individuals may be unaware of the very fact that they have suffered a brain injury (Sherer, Boake, Levin et al., 1998). Impaired awareness also occurs for discrete domains of functioning. One of the most striking manifestations is anosognosia for hemiplegia where individuals deny impairment of the affected limb. This condition is highly prevalent following right-hemisphere stroke occurring in as many as 28 percent of individuals in the acute phase (Starkstein, Federoff, Price et al., 1992).

There are a number of studies demonstrating impaired awareness for cognitive changes following brain injury. This is particularly prevalent following closed head injury (Flashman & McAllister, 2002). Impaired awareness has been empirically demonstrated for memory loss, intellectual function, visuo-spatial function, and other cognitive deficits (Anderson & Tranel, 1990; Boake et al., 1995, Prigatano, 1999c).

Awareness may also be compromised for behavioural and social functioning and occurs even when cognitive and other difficulties are readily acknowledged (McKinlay & Brooks, 1984). Fahy, Irving and Millac (1967) found that while patients exhibited some awareness of cognitive and speech difficulties, they rarely acknowledged changes in behaviour such as impulsivity and affective instability.

Dimensions of impaired awareness

Flashman, Amador and McAllister (1998) describe a schema with three dimensions of impaired awareness. The first dimension is that of knowledge and refers to whether an individual can identify a specific deficit. The second dimension involves the emotional response of the individual towards their difficulties. The third dimension is the ability to comprehend the impact or consequences of the impairment on everyday life.

Fleming and Strong (1995) have also delineated a model to describe three dimensions of self-awareness. The first dimension is awareness of the apparent physical, cognitive, behavioural, and emotional changes. The second aspect refers to awareness of the consequences of the impairments on aspirations such as work, relationships, and leisure. The third dimension of self-awareness is the ability to set realistic goals.

A further facet of awareness is the *depth of awareness*. There are varying depths of impaired awareness that encompass partial and complete unawareness. As such impaired awareness is not an all-or-nothing phenomenon. Awareness can also vary in an individual across different domains (Fischer, Trexler, and Gauggel, 2004; Gasquoine, 1992; Toglia & Kirk, 2000). Research studies have for example found that

brain injury survivors tend to be more aware of their physical than their cognitive and behavioural impairments (Anderson & Tranel, 1989; Powell, Machamer, Temkin, & Dikmen, 2001; Prigatano, 1996).

Impaired awareness must also be considered within a temporal framework. Research on the course of impaired awareness indicates that it is most pronounced in the acute stages often leading to partial or full remission. The most salient example is that of anosognosia for hemiplegia where resolution is often dramatic (Starkstein et al., 1992). Powell et al. (2001) assessed 157 TBI survivors at one month, six months, and twelve months after injury. They found that TBI survivors tended to become more aware of cognitive impairments over time. Although impaired awareness may decrease over time some individuals may minimise the severity of acquired deficits for years following ABI (Flashman & McAllister, 2002).

Explanations of impaired awareness

Neuroanatomical and neuropsychological evidence

Various brain regions have been implicated in impaired awareness. Damage to the right hemisphere and specifically the right parietal lobe is thought to be significant in impaired awareness (McGlynn & Schacter, 1989). Anderson and Tranel (1989) found that impaired awareness was associated with unilateral right-hemisphere damage. This has been shown for anosognosia for hemiplegia and hemianopia and is thought to involve the breakdown of sensory or cognitive systems (Giacino & Cicerone, 1998). Impaired self-awareness and executive unawareness have been shown to be associated

with damage to the prefrontal cortex (Stuss & Anderson, 2004). This suggests that different types of impaired awareness are associated with distinct brain regions.

Diffuse damage theories of impaired awareness (Ownsworth, McFarland, & Young, 2002) implicate the degree and severity of brain injury as being causal. A number of studies have investigated the association between injury severity and general cognitive decline with awareness. A review of research by Ownsworth et al. (2002) concluded that indices of severity such as post-traumatic amnesia and Glasgow Coma Score were not generally associated with deficits in awareness. In regard to intellectual functioning the evidence was more equivocal with 4 out of 10 studies suggesting that general cognitive decline contributed to impaired awareness.

Neuropsychological testing has also been utilised to substantiate neurologically based theories of impaired awareness. Care must however be taken when drawing inferences about neuroanatomy based on neuropsychological test performance (Clare 2004a). Anderson and Tranel (1989) investigated impaired awareness in 100 individuals with cerebral infarction, dementia, or head trauma. They found that impaired awareness was associated with poorer performance on intelligence tests. Their explanation for this finding was that intellectual impairment reflects multiple neuropathological processes that accords with the multifaceted nature of metacognition required for awareness. Starkstein, Federoff, Price et al. (1993) investigated neuropsychological deficits in 24 stroke patients with anosognosia. They found that individuals with anosognosia had significantly more deficits on 'frontal lobe' tests but not on memory tests. More recently Bogod, Mateer and MacDonald (2003) investigated the relationship between self-awareness and measures of executive functioning in a group

of 40 TBI survivors. They found that measures of executive functioning were predictive of impaired self-awareness. Finally Ownsworth (2004) has reported an association between impaired self-awareness and an aspect of executive functioning, namely verbal fluency.

Contradictory evidence has also been produced regarding the impaired awareness-neuropsychological outcome relationship. Prigatano, Altman and O'Brien (1990) failed to find an association between neuropsychological test scores and impaired awareness of socio-emotional deficits. They concluded that impaired awareness of behavioural limitations might reflect a disturbance not adequately sampled by traditional neuropsychological measures. Newman, Garmoe, Beatty and Ziccardi (2000) examined the relationship between self-awareness and neuropsychological functioning in acute brain injury patients. They did not find an association and concluded that self-awareness in the early stages of recovery represents a unique construct.

Heteromodal cortex theory

Prigatano (1991, 1999a) has developed a neurologically based model of impaired awareness implicating damage to the heteromodal cortex. The heteromodal cortex refers to the association cortex. It involves large areas of the prefrontal and frontal cortex, inferior parietal lobule, supramarginal and angular gyri, and portions of the temporal lobe.

Prigatano (1991) argues that different forms of impaired awareness emerge from damage to different areas of the heteromodal cortex. Four disorders of impaired

awareness are proposed. They are the frontal-heteromodal disorder which impairs awareness of social, behavioural and executive deficits; parietal-heteromodal disorder which limits awareness of sensorimotor function; temporal-heteromodal disorder which impairs insight into memory, visual, and auditory problems; and occipital-heteromodal disorder which impairs awareness of disturbances of cortical blindness and hemianopia.

Hierarchy of Brain Function Model

The Hierarchy of Brain Function Model, developed by Stuss and Benson (1986), implicates frontal lobe dysfunction as being pivotal in the pathogenesis of impaired awareness. This model posits that the frontal lobes are involved in the process of performance monitoring. Impaired awareness can be viewed as a deficit in self-monitoring.

This theory rests within a hierarchical model of brain functioning consisting of four interactive levels with self-awareness being the highest of all brain activities. Functions such as basic arousal, attention, language, and memory are viewed as complex systems with their own organisation operating on a fixed, over-learned, automatic level (Stuss, 1991). The frontal lobes are said to interact with and mediate the posterior/basal brain regions providing sequencing, integrating, and controlling functions. Self-awareness or self-reflection is said to be the highest attribute of the frontal lobes. Impaired awareness arises when frontal system damage occurs and the frontal lobes are not able to provide this integrative function.

The model accounts for the varying manifestations of impaired awareness by proposing that varying degrees and combinations of brain lesions produce different forms of the disorder. As such damage to different levels of the brain functioning hierarchy will result in different manifestations of impaired awareness (Clare, 2004a, Stuss & Anderson, 2004).

Motivational theories

In comparison to neurological explanations, motivational theories implicate the role of psychological factors in the development of impaired awareness following ABI, and use the term *denial* to describe this. Prigatano and Klonoff (1998) state that denial after brain injury appears to be an indirect result of the neurological injury as it reflects the individual's attempt to utilise pre-morbid coping strategies to process the knowledge of partially recognised impairments.

Weinstein and Kahn (1955) originally advanced the position that psychodynamic factors play a significant role in impaired awareness. They hypothesised that personality factors (e.g. perfectionism) predating the injury are involved in the manifestation of impaired awareness. Within this framework denial is viewed as an adaptive coping response (Prigatano & Weinstein, 1996). Kortte, Wegener and Chwalisz (2003) have investigated coping strategies associated with denial and anosognosia. They found that avoidant coping strategies were more frequently employed by individuals assessed as exhibiting denial.

Denial of impairments can also be viewed as a form of psychological defence mechanism. Kihlstrom and Tobias (1991) have delineated defence mechanisms

relevant to denial of impairments. *Rationalisation* may occur when the individual produces seemingly reasonable explanations for their performance (e.g. "I was never any good at solving puzzles"). With *reaction formation* an individual could state that their abilities are suddenly now much better than they have ever been. Other forms of defence mechanisms could include *repression*, *projection* and *displacement*.

Clare (2004a) elucidates the value of denial-based explanations of impaired awareness by directing attention to the social constructionist nature of unawareness. Evidence of impaired awareness is most likely to be elicited in a social act usually between clinician and patient. As such contextual, motivational, and other psychological influences will affect how individuals present themselves.

Motivational explanations are also subject to criticism as they are not able to account for the full range of phenomena found in disorders of awareness (McGlynn & Schacter, 1989). Motivational theories are not able to explain findings that associate impaired awareness with certain brain sites. Further criticism focuses on the temporal course of impaired awareness after ABI. It has been shown that awareness generally increases with time from injury, when this would be contrary to expectations for denial (McGlynn & Schacter, 1989).

The Pyramid Model of Awareness

Impaired awareness has traditionally been defined as lack of knowledge of one's deficits (Toglia & Kirk, 2000). Crosson, Barco, Velozo et al. (1989) have delineated a model of awareness that expands the focus to include self-monitoring and anticipation of performance. This model is referred to as the Pyramid Model of Awareness.

Three interdependent levels are identified within a hierarchical structure. *Intellectual awareness* refers to the ability to understand that a particular function is impaired. Intellectual awareness can be limited by a lack of adequate knowledge about the consequences of ABI or the neurological injury itself. Neurological injury may cause severe deficits in abstract reasoning or memory functioning thereby limiting an individual's capacity to understand, remember and process knowledge of deficits. Neuroanatomical injury sites implicated in impaired intellectual awareness include dorsolateral, frontal, basal forebrain, bilateral mesial temporal, and diffuse regions.

Intellectual awareness forms the foundation for the subsequent levels of awareness, namely *emergent awareness* and *anticipatory awareness*. Emergent awareness refers to the ability to recognise a problem while it is occurring. It is suggested that emergent awareness may be the residual effects of the more florid anosognosia seen acutely after right hemisphere injury, for example anosognosia for hemiplegia, thereby implicating the role of the inferior parietal lobe. Anticipatory awareness is the ability to foresee that a problem will occur and is regarded as the most advanced form of awareness. Deficits in anticipatory awareness are related to deficits in frontal lobe functioning.

The Pyramid Model implicates a wide array of brain regions in the emergence of impaired awareness and accords with neuroanatomical explanations such as those suggested by Prigatano (1991; 1999a). It provides an explanation for the different manifestations of impaired awareness, thereby suggesting that awareness is not a unitary concept. It also acknowledges the role of psychological factors (denial) as an additional barrier to awareness.

Comprehensive Dynamic Interaction Model

Toglia and Kirk (2000) have expanded the Pyramid Model to develop a model of awareness that draws on cognitive psychology, social psychology, and neuropsychology. It rejects the static nature of the Pyramid Model and proposes a dynamic interaction between knowledge, beliefs, task demands, and the context of the situation.

Toglia and Kirk (2000) view awareness within a framework based on metacognition. Metacognition in this model refers to the conscious knowledge of cognitive processes such the ability to monitor and regulate ongoing processes while engaging in a task. The model describes a set of interrelated and interactive processes that contribute to awareness. These include domain of concern, depth of awareness, knowledge, self-knowledge, beliefs, on-line awareness, external influences, and response to feedback.

This model presents a wider range of influences that could contribute to impaired awareness. The dynamic nature allows for the introduction of influences on awareness not considered by other models such as cultural influences and belief systems.

Dissociable Interactions and Conscious Experience

This model presents a theoretical integration of available evidence on impaired awareness (Schacter, 1990). It proposes the existence of a conscious awareness system (CAS; Schacter, 1989), a system distinct from lower level modular systems concerned with cognitive functions such as language, memory, and perception. The CAS receives information from the modular systems when there is a change in their

baseline resting state. This causes the CAS to activate and the individual experiences conscious awareness of the information being processed.

The model suggests that the CAS is a posterior brain system involving the inferior parietal lobes and connecting structures located in the corpus callosum. The existence of an executive system is also proposed, which is involved in the initiation, organisation, and monitoring of complex sequences and ideas. The executive system is said to be located in the frontal structures of the brain.

In this model impaired awareness is linked to the specific system that has been affected. The model proposes that impaired awareness arises from damage to the posterior CAS, the anterior executive system, or connecting systems. Damage to the CAS itself would result in unawareness of all neuropsychological deficits, as it is no longer able to process and respond to the information received from the modular systems. Selective disconnection between the CAS and a cognitive module would produce a specific form of impaired awareness such as that seen in anosognosia for hemiplegia.

Impaired awareness due to a disruption of the frontal executive system can result from damage to the executive system itself or as a result of a disconnection between the CAS and the executive system. Both forms of damage would have similar consequences, namely impaired awareness of complex functions such as problem-solving and social, behavioural, or personality changes.

This model provides a theoretical account of impaired awareness that is largely consistent with the available clinical and research literature implicating parietal and frontal regions in impaired awareness (McGlynn & Schacter, 1989). It is also consistent with explanations such as those of Stuss and Benson (1986). The limitations of the model extend to its inability to account for evidence showing a link between impaired awareness and right hemisphere damage. In addition it does not provide an account of the psychological and social factors affecting impaired awareness (Clare, 2004a).

Aspects of theoretical models of impaired awareness have been subjected to empirical research. Various instruments have been developed to measure impaired awareness, primarily for research purposes. The following section provides an overview of the methods utilised for the assessment of impaired awareness.

Assessment of impaired awareness

A range of methods has been proposed to assess awareness. These include clinician ratings of awareness, ratings based on patient versus significant other's perceptions, and the difference between patient prediction of and performance on cognitive or functional tasks.

Clinician ratings of awareness utilise open-ended (Giacino & Cicerone, 1998), semi-structured (Starkstein et al., 1992) or structured interviews (Fleming, Strong, & Ashton, 1996). The presence of impaired awareness is ascertained either by clinical decision or by the use of a scoring method. The determination of impaired awareness

by clinical decision is underpinned by the assumption that it is a symptom reliably elicited in a clinical interview (Clare, 2004b). This method is relatively unsophisticated and subjective and may be more applicable for more obvious anosognosia (Campodonico & McGlynn, 1995). In contrast Fleming et al. (1996) have developed the Self-Awareness of Deficits Interview (SADI) as a means of gathering both quantitative and qualitative information on self-awareness. The questionnaire gathers data in three areas, (1) self-awareness of deficits; (2) self-awareness of functional implications of deficits; and (3) ability to set realistic goals. Studies of the SADI have produced good interrater reliability of 0.82 (Fleming et al., 1996), 0.85 (Fleming, Strong, and Ashton, 1998), and test re-test reliability 0.94 (Simmond & Fleming, 2003). Preliminary concurrent validity data have also been produced for the SADI (Ownsworth, McFarland, & Young, 2000a).

The interview method is advantageous in that it allows for a more explorative, in-depth assessment of impaired awareness. Clare (2004b) indicates a potential disadvantage of the interview method in that the social context of a clinical interview might predispose an individual to present him or herself in a positive light. In addition it requires intact verbal comprehensive and expressive abilities (Flashman & McAllister, 2002).

Self-awareness is most commonly assessed by comparing patient self-ratings with those of significant others or clinicians (Simmond & Fleming, 2003). Most studies indicate that patients comparatively underreport their cognitive, behavioural and emotional symptoms (Sherer et al., 1998). This method uses a discrepancy score (patient vs. relative or patient vs. clinician) to provide a measure of impaired

awareness. Two such instruments are the Patient Competency Rating Scale (PCRS; Prigatano, Fordyce, Zeiner et al., 1986) and the Awareness Questionnaire (AQ; Sherer, Bergloff, Boake et al., 1998)

The PCRS was developed as a method for comparing patients' self-ratings of competencies with those of relatives and clinicians. It assesses competencies in areas such as activities of daily living, cognitive functioning, interpersonal functioning and emotional regulation. There are three forms namely, patient, family/significant other, and clinician rating. Degrees of impaired awareness are established with the discrepancy score. The AQ was developed as an alternative research tool to the PCRS (Sherer, Hart, & Nick, 2003) and requires pre and post-injury comparisons to be made.

A concern regarding this approach is whether discrepancy scores accurately reflect impaired awareness (Trosset & Kaszniak, 1996). A further concern relates to the likelihood of a significant other providing an accurate and valid rating (Toglia & Kirk, 2000). Informants may not be as familiar with the behaviour in question and may consequently provide an inaccurate rating (Leathem, Murphy, & Flett, 1998). Fleming et al. (1996) identified further factors that may influence the accuracy of relative ratings including stress levels, personality, and length of time since injury. There are some indications that relatives may also deny the disability (McKinlay & Brooks, 1984). Clinicians may also not provide an objective rating if biased by factors such as the likeability of the individual (Toglia & Kirk, 2000).

Comparing an individual's prediction of performance with actual performance represents an additional approach to assessing awareness (Allen & Ruff, 1990). The individual is required to estimate how well they can perform tasks and a comparison is made with actual performance (Boake et al., 1995). Campodonico and McGlynn (1995) contend that this appears to be the most concrete and contextually based method of assessing impaired awareness. Allen and Ruff (1990) found that individuals with TBI tended to underestimate their difficulties in comparison to performance on a range of neuropsychological measures. A major drawback of this approach relates to the artificialness of the tests (Campodonico & McGlynn, 1995). An individual may find it difficult to predict performance on a task with which he or she has no familiarity. There may be also a discrepancy between performance on neuropsychological measures and functional abilities in everyday life (Sbordone, 2001).

Measures of impaired awareness have primarily been developed as research tools. They have, for example, been utilised to examine the association between impaired awareness and factors relevant to rehabilitation. The relationship between impaired awareness and outcome will be examined in the following section.

Impaired awareness and outcome

Studies advance the notion that impaired awareness may have a negative impact on the effectiveness of rehabilitation (Nockleby & Deaton, 1987). It has been shown that impaired awareness can complicate treatment by lowering motivation and engagement in the rehabilitation process as well as increasing the likelihood of pursuing unrealistic goals (Ezrachi, Ben-Yishay, Kay et al., 1991; Prigatano & Wong,

1999). Malec and Degiorgio (2002) studied the characteristics of successful and unsuccessful completers of brain injury rehabilitation. They concluded that individuals with impaired awareness required a higher level of clinical input in rehabilitation even when their disabilities were relatively circumscribed.

Impaired awareness has been associated with poorer behavioural outcome and lower independent living status. Trudel, Tryon, and Purdum (1998) investigated the relationship between chronic impaired awareness and outcome in a group of 63 TBI survivors. They found that impaired awareness was significantly associated with maladaptive behaviour and greater distractibility. Hoofien, Gilboa, Vakil, and Barak (2004) examined the relationship between awareness and daily functioning in 61 persons with TBI. They found that individuals with TBI who overestimated their cognitive abilities had poorer daily functioning and more behaviour disturbance than those who did not overestimate their abilities. Malec and Moessner (2000) studied the relationship between impaired self-awareness and treatment outcome in 62 individuals participating in a day treatment program. Their results indicated that higher awareness was correlated with positive behavioural changes and independent living. Hartman-Maeir, Soroker, Ring, and Katz (2002) evaluated the impact of awareness of deficits on rehabilitation outcome in a group of stroke survivors. They found that awareness at admission was predictive of treatment outcome at discharge for individuals with right hemisphere damage.

Numerous studies have focussed on the relationship between awareness and employment outcome. Poor awareness and unrealistic expectations are often described as impediments to successful vocational integration following rehabilitation

(Ben-Yishay, Silver, Piasetsky, & Rattock, 1987). The results of studies investigating this association have however been somewhat mixed. Fordyce and Roueche (1986) studied 28 individuals during rehabilitation and failed to find an association between awareness levels and vocational outcome. Cavallo, Kay, and Ezrachi (1992) studied 34 persons with mild to severe TBI. They also did not find an association between impaired awareness and return to work rates.

In contrast Walker, Blankenship, Ditty and Lynch (1987) studied 25 individuals with TBI in a day treatment program. They found that individuals with better awareness were more likely to have productive activities outside the home than those with poor awareness. Ezrachi et al. (1991) examined predictors of vocational status at follow-up in a sample of 59 persons with TBI. They found that accuracy of self-appraisal at admission was predictive of vocational status six months after discharge. Sherer, Bergloff, Levin et al. (1998) studied 66 individuals with mild to severe TBI who were treated in a rehabilitation program. A positive relationship was found between accurate self-awareness and favourable long-term employment outcome. More recently Sherer, Hart, Nick et al. (2003) investigated the relationship between impaired self-awareness in the acute phase of TBI and employment outcome. Using a sample of 129 individuals they found that early impaired self-awareness was negatively associated with employability at discharge from inpatient rehabilitation.

Although the results are mixed there does appear to be a trend indicating that impaired awareness is a negative factor in rehabilitation and functional outcome after brain injury. Sherer et al. (2003) posits that further research is needed to determine if treatment programmes for impaired awareness enhance functional outcomes.

Relationship between impaired awareness and emotional distress

Increased awareness of deficits is generally seen as a positive development during neuro-rehabilitative efforts (Fleming & Strong, 1995). A further important consideration following brain injury is the incidence and treatment of emotional distress (e.g. depression). Depression appears to be a common consequence of both TBI and stroke (Glenn, O'Neil-Prizzi, Goldstein et al. 2001; Jorge, Robinson, Moser et al., 2004; Kersel, Marsh, Havill & Sleigh, 2001; Koponen, Taiminen, Portin et al. 2002; Kreutzer, Seel, & Gourley, 2001; Tateno, Kimura, & Robinson, 2002). In a large-scale prevalence study of depression following TBI, Kreutzer et al. (2001) found that 42 percent of those studied (722 patients) met the criteria for a diagnosis of depression. Ramasubbu, Robinson, Flint et al. (1998) found an incidence rate of 26 percent for moderate and major depression in acute stroke patients.

Depression following brain injury has been linked to factors such as lesion location (Jorge et al., 2004; Narushima, Kosier, & Robinson, 2003), pre-morbid psychiatric history (Federoff, Starkstein, Forrester et al. 1992; Tateno et al., 2002), poor functional outcome (Gomer-Hernandez, Max, & Kosier, 1997), and demographic and injury-related variables. An association between depression and awareness of deficits following brain injury has also been reported (see Fleminger, Oliver, Williams & Evans, 2003).

Depressed mood has been linked with increased levels of awareness of deficits (Godfrey, Partridge, Knight, & Bishara, 1993). Impaired awareness has been shown to be particularly prevalent in the early stages of recovery with partial or full

resolution occurring with the passage of time (Ownsworth and Oei, 1998). Depression may be a consequence of an increase in awareness as the individual gradually acknowledges the existence of impairments (Gainotti, 1993). Godfrey et al. (1993) compared TBI patients who were at six months, one year, or two–three years post injury. Using a cross-sectional design, they found that impaired awareness was greatest in the six-month group while the one year and two–three year group had greater levels of emotional dysfunction. They concluded that increased awareness was associated with an increased risk for emotional dysfunction.

Gasquione (1992) studied the relationship between affective state and awareness of sensory and cognitive change in 42 individuals with TBI. Participants were between 1.5 and 56 months post injury. He found that emotional dysphoria was positively correlated with awareness of neurobehavioural consequences. Wallace and Bogner (2000) investigated the relationship between emotional distress and awareness of deficits in 50 individuals with brain injury. They found moderate to weak relationships between awareness and emotional distress. They also found, contrary to expectations, that awareness was somewhat poorer for individuals who had sustained their injuries further back in time. Fleming et al. (1998) also found a significant relationship between self-awareness and depression. They found that increased awareness after brain injury was associated with higher levels of depression.

Prigatano (1997) provides an alternative account of the relationship between awareness and mood. He suggests that persisting impaired awareness may result in frustration, disappointment and failure as the individual tries to resume pre-injury aspirations. This may culminate in emotional distress such as depression and anxiety.

Ownsworth and Oei (1998) postulate that the likelihood of depression increases when an individual with impaired self-awareness attempts to resume pre-morbid social and vocational roles, and then experiences failure.

Evans, Sherer, Nakase-Thompson et al. (2003) studied 75 TBI patients during post-acute inpatient rehabilitation. They found that poorer self-awareness was associated with higher levels of depression. Viguier, Dellatolas, Gasquet et al. (2001) investigated the psychological adjustment of adolescent and young adult inpatients. They found that for TBI patients, depression was compatible with a degree of lack of awareness of cognitive and behavioural problems. Fleming, Connell, Tooth, and Strong (2002) explored the relationship between self-awareness and emotional adjustment over a period of transition from hospital to the community. They found that while self-awareness increased over this transition period it was not accompanied by an increase in emotional distress for TBI survivors.

There appears to be some disparity in the research findings as to the direction of the association between depression and awareness. One aspect that could account for the different findings is *time-since-injury*. Earlier in the recovery process an increase in awareness might lead to emotional distress while during the later stages of recovery persisting impaired awareness may result in depression. Lezak (1987) found that individuals with TBI evidenced their highest levels of anxiety and depression 7 – 12 months post-injury. Ownsworth and Oei (1998) postulate that this is the recovery period in which individuals are most likely to gain awareness of the devastating changes in their lives and that this may result in a depressive reaction. Ownsworth and Oei (1998) also suggest that if individuals do not gain awareness of their limitations

during the first year it may result in later frustration and failure. Toglia and Kirk (2000) state that individuals with ABI who overestimate their performance may experience an unexpected outcome (failure), which in turn leads to a decreased sense of achievement and low self-efficacy. Over the longer term this could culminate in depression and other forms of emotional disturbance.

Given the discrepancy in research findings on the relationship between awareness and depression, alternative explanations must also be considered. In this regard Fleminger et al. (2003) propose that depression may lead to improved awareness. The mechanism they propose is that of *depressive realism* whereby a change in attribution style accompanying depression results in a more accurate view of reality. This theory has not yet been investigated with an ABI group. Finally, it must also be noted that awareness and depression may be independent processes, each with distinctive risk factors and temporal patterns following brain injury.

A potential association between awareness and depression has theoretical and clinical significance. Addressing emotional functioning following brain injury is currently considered a pivotal aspect of rehabilitation (Williams & Evans, 2003). If depression fluctuates with levels of awareness, issues are raised as to how and whether impaired awareness should be addressed in rehabilitation. The argument has been put forth that it may not be necessary to address impaired awareness during rehabilitation (Sohlberg, Mateer, Penkman et al., 1998). Most studies however appear to advocate an approach that focuses on the treatment of emotional distress and impaired awareness concurrently (Flashman & McAllister, 2002).

Treatment of impaired awareness

A variety of approaches to improve awareness have been advocated. Sherer, Oden, Bergloff et al. (1998) categorize these strategies as follows: direct feedback, experiential feedback, education, and psychotherapy.

Direct feedback refers to the provision of information by the clinician based on performance during a training session. This feedback could refer to cognitive, behavioural or social performance. Videotaped feedback has for example been used to provide critique on social behaviour (Alexy, Foster, & Baker, 1983). Bergquist and Jacket (1993) advocate the use of feedback to aid with appropriate goal setting. They recommend that this be accomplished within a supportive and non-directive therapeutic relationship. Experiential feedback is regarded as a valuable method in both the acute and postacute phases of treatment (Langer & Padrone, 1992; Sherer et al., 1998). It provides the individual an opportunity to complete a task in a naturalistic setting (e.g. shopping) in order to experience potential difficulties first hand. Impaired awareness can also be addressed by direct education of both patients and their significant others regarding the cognitive, behavioural, and emotional sequelae of traumatic brain injury (Fordyce & Roueche, 1986).

Feedback and educative approaches to improve awareness have been criticised on the grounds that they may elicit defences aimed at entrenching an individual's position regarding his or her current functioning (Bieman-Copland & Dywan, 2000).

Psychotherapy has been advocated as a technique that may be beneficial in the treatment of impaired awareness and provides an adjunct approach to feedback and education methods (Langer and Padrone, 1992; Prigatano, 1997). It is said to address

the underlying psychological adjustment issues that play a role in the manifestation of impaired awareness (Sherer et al., 1998).

Many of the methods described above are often embedded within comprehensive neuropsychological rehabilitation programmes that regard the improvement of awareness as a cornerstone of treatment (Ben-Yishay & Prigatano, 1990; DeHope & Finegan, 1999; Fordyce & Roueche, 1986; Prigatano, 1997; Sherer et al., 1998). Sherer et al. (1998) describe a neuropsychological rehabilitation programme that seeks to address impaired awareness during all treatment activities. The use of family interventions, peer feedback, education, roleplay/video feedback, real world experiences, and psychotherapy are said to present opportunities to address impaired awareness. Prigatano (1997) describes how general rehabilitation strategies are utilised to enhance self-awareness. For example, cognitive retraining exercises allow for the provision of feedback on current and previous performance levels, while psychotherapy is seen as an important technique if patients experience an affective reaction to the treatment process or if they fail to engage in the program. It is possible that impaired awareness may underlie both of these responses (Langer and Padrone, 1992).

While many strategies have been suggested to address impaired awareness little empirical evidence exists to demonstrate their effectiveness (Flashman & McAllister, 2002). Most of the reported evidence falls into the categories of small group studies or case reports. Chittum, Johnson, Chittum et al. (1996) examined the use of a board game format to teach awareness to three adults who exhibited behavioural difficulties. They focussed on awareness of personal deficits in cognition and behaviour. All

participants responded positively to the training and were able to answer more questions correctly at the end of the programme and at follow-up. There was also some generalisation to novel questioning at follow-up periods.

Ownsworth, McFarland and Young (2000b) investigated a 16-week group support programme involving components of cognitive rehabilitation, cognitive-behavioural therapy, and social skills training to improve self-awareness and psychosocial functioning in a group of 21 individuals. Post-intervention assessment revealed that self-regulation skills improved significantly. Six-month follow-up indicated that participants generally maintained these gains. There was a high level of pre-intervention intellectual awareness in this group and this remained essentially unchanged over the course of the study.

Youngjohn and Altman (1989) described the use of a performance-based group approach to improve awareness in six patients with TBI. Participants were given feedback of their performance on recall and arithmetic tasks. Results showed more accurate prediction of performance after the intervention on both the cognitive tasks. There was some suggestion that participants were able to readjust their stated goals after the group, thereby indicating some generalisation.

Case study methodology has also been used to investigate treatment of impaired awareness. Schlund (1999) described the use of practice and feedback on a recall task to improve awareness in memory functioning for an individual five years post TBI. The intervention was able to reduce the participant's inaccurate reporting of his memory functioning. Bieman-Copland and Dywan (2000) used a behavioural

approach to reduce behaviour problems in a woman with profound anosognosia. The use of direct feedback and education was specifically avoided. While significant gains were made in the amelioration of behavioural problems no change in anosognosia was found. Rebmann and Hannon (1995) used feedback and positive reinforcement to improve awareness of memory deficits in three individuals with severe TBI. All three individuals showed an improvement in their ability to predict their performance on memory tasks.

In summary it appears that the treatment of impaired awareness is considered an important component of neuropsychological rehabilitation and a variety of strategies exist to address impaired awareness. Relatively few studies have however empirically examined these treatment strategies. Sherer et al. (1998) suggest that additional research should address the effectiveness of strategies, generalisation of treatment effects to real world functioning, and the relationship to treatment gains in long-term outcome.

Summary and conclusions

The resolution of impaired awareness following brain injury has emerged as an important theoretical and clinical issue. Research has focussed on definitional, phenomenological, theoretical, and treatment considerations. The literature on the etiology of impaired awareness implicates the neurological insult as being the primary contributing factor whilst there is acknowledgement of the role of psychological variables. The distinction between impaired awareness and denial is rarely made in the literature and requires further investigation and delineation in empirical studies.

There is considerable variability in the findings regarding the relationship between impaired awareness and variables such as depression and neuropsychological functioning. Deficient executive functioning has emerged as an important factor in understanding impaired awareness and influential theories of awareness implicate the frontal lobes in impaired awareness. The studies that have investigated this aspect have delivered mixed results and have utilised a wide range of measurement instruments. Further research using standardised, accessible instruments, would be an important contribution to the field.

The relationship between depression and awareness has received significant attention in the literature. There are however different perspectives as to the directionality of this relationship and the psychosocial processes involved. As such there is a need for further research to explore this relationship. Future research must consider possible contributing factors such as time since injury and persisting impaired awareness.

Research studies have demonstrated that awareness is likely to be a significant factor in neurorehabilitation efforts. It has been shown to effect treatment, daily functioning, and employment outcome. As such it requires remediation in order for rehabilitation to succeed. Although many programmes target awareness as a treatment goal there are relatively few outcome studies on the treatment of impaired awareness.

Further empirical research is needed on treatment approaches for impaired awareness. New methods of treating impaired awareness should be explored and take cognisance of the neurobehavioural profiles of individuals with impaired awareness. For example if impaired awareness is associated with executive deficits then a more

concrete/tangible approach where individuals do not have to rely exclusively on higher level conceptual reasoning processes may be more appropriate. In this regard it would be worthwhile to investigate the neuropsychological profiles of individuals who benefit from interventions. In addition to this, treatment studies could examine the outcome of improving awareness on factors such as depression given the possible relationship between awareness and mood.

It is clear that the area of impaired awareness following ABI presents many complex theoretical and clinical challenges. These challenges can only readily be addressed with empirical research. This research should ideally build on previous studies in order to promote greater clarity in this field.

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Appendix A. Manuscript submission guidelines: Rehabilitation Psychology

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SECTION 3. RESEARCH PAPER

To be submitted to: *Brain Injury*

Feedback of brain-imaging findings: Effect on impaired awareness and mood in acquired brain injury

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Feedback of brain-imaging findings: Effect on impaired awareness and mood in acquired brain injury

Abstract

Primary objective: To investigate the utility of feedback of brain-imaging findings as an intervention for improving impaired awareness, depression and anxiety levels.

Research design and methods: A prospective within-subjects repeated measures design was used with an intervention sample of 17 adults with acquired brain injury. Baseline and post-intervention measures included self-report and questionnaire-based self-awareness instruments and self-report questionnaires for depression and anxiety. Participants also completed a range of neuropsychological tests.

Intervention: The intervention consisted of a session where a Consultant Neurologist explained the findings of brain scans in terms of pathological findings and possible neurobehavioural outcome.

Results: Scores on measures of unawareness and two of three mood measures decreased significantly following the intervention. This improvement was maintained at two-week follow-up.

Conclusion: Individuals with an acquired brain injury may benefit from a feedback procedure where the findings of brain scans are presented.

Feedback of brain-imaging findings: Effect on impaired awareness and mood in acquired brain injury

Introduction

Acquired brain injury (ABI) results in a characteristic spectrum of physical, cognitive, and behavioural consequences [1]. A considerable percentage of individuals with ABI are unable to appreciate their deficits and comprehend the effect of these impairments on daily functioning [2-4]. Impaired awareness of deficits has received significant interest in the brain injury and neurorehabilitation literature [5-10]. This appears to be related to the significant impact that impaired awareness can have on post-injury recovery. Impaired awareness can lower motivation and engagement in the rehabilitation process, result in the pursuit of unrealistic goals, and prevent a successful outcome [11]. It has been shown to impact negatively on rehabilitation progress [12], behavioural adaptation [13-15], daily functioning [14], and employment [16, 17].

Various methods have been developed for the measurement of impaired awareness [18]. These include the discrepancy based approach [19] and interview methods [20]. In the discrepancy based approach patients' self-ratings of competencies or functional limitations are compared with clinician or significant others' ratings [21, 22]. A discrepancy between the patient score and significant other/clinician score is considered an indicator of impaired awareness. Two such instruments, the Patient Competency Rating Scale (PCRS) [21] and the Awareness Questionnaire (AQ) [22] have established reliability and validity [19]. An example of the interview method is the Self-Awareness of Deficits Interview (SADI) developed by Fleming et al. [20].

The SADI is an interviewer-scored structured technique that provides qualitative and quantitative information on self-awareness post-ABI. It assesses self-awareness in three domains namely, self-awareness of deficits, self-awareness of functional implications of deficits, and ability to set realistic goals.

Measures of impaired awareness have been developed as research tools to aid in the exploration of relationships between awareness and neuroanatomical, neuropsychological, or psychological aspects of ABI [9, 20]. Neuropsychological testing has been employed to investigate explanatory hypotheses of impaired awareness such as those postulated by Stuss and Benson [23, 24], Schacter [25] and Crosson et al. [26]. These theories have in common their implication of the frontal lobe structures in disorders of awareness. The research evidence is largely equivocal regarding a relationship between neuropsychological functioning and impaired awareness [27].

Some studies have found a positive relationship between executive functioning and awareness. For example Starkstein et al. [28] investigated neuropsychological deficits in stroke patients with and without impaired awareness. They found that patients with impaired awareness had significantly more deficits in frontal lobe-related tasks than those without. A study by Bogod, Mateer, and MacDonald [29] compared functioning on tests of executive ability with evaluations of awareness using the SADI and a discrepancy score rating. They found that the SADI correlated with 'dorsolateral' and 'orbito-frontal' measures of executive functioning with poorer awareness implicating poorer test performance. Finally Ownsworth [30] has recently reported an association between impaired self-awareness as assessed with the SADI and an aspect of

executive functioning, namely verbal fluency. These studies provide partial support for the theoretical models of awareness such those of Stuss and Benson [23, 24]. It is however worth repeating that other studies have failed to find this association [31].

The relationship between impaired awareness and emotional distress has also received recent attention [32]. Gainotti [33] has highlighted a possible link between increased levels of awareness and the onset of depressed mood. Within this framework emotional distress is viewed as a consequence of increasing awareness as an individual begins to recognize the existence of impairment and disability. Godfrey et al. [34] compared TBI patients at six months, one year, and two-three years post-injury. They found that impaired awareness was higher in the six-month group while the one-year and two-three year group evidenced greater levels of emotional dysfunction. They concluded that return of awareness was associated with a risk for increased emotional dysfunction. Gasquione [35] studied the relationship between affective state and awareness of sensory and cognitive change in 42 individuals with TBI. He found that emotional dysphoria was significantly and positively correlated with awareness of neurobehavioural change. Further evidence of this hypothesis has been garnered from the studies of Wallace and Bogner [36] and Fleming et al [37].

Prigatano [38] offers an alternative account on the relationship between awareness and emotional distress. He argues that impaired awareness may cause an individual to pursue unrealistic goals. If a person then fails, and experiences frustration and disappointment, it could culminate in depression. In a similar fashion Ownsworth and Oei [39] postulate that the likelihood of depression increases when an individual with persisting impaired awareness attempts to resume pre-morbid social and vocational

roles and experiences failure. Support for this argument can be found in the research literature. Viguier et al. [40] found that depression and anxiety was compatible with impaired awareness in adolescent and young adult TBI patients. Evans et al. [41] studied 75 TBI patients during post-acute rehabilitation. They found that poorer self-awareness correlated with increased depression. Fleming et al. [42] studied the association between self-awareness and emotional adjustment through the transition from hospital to the community in a group of 23 TBI survivors. They found that an increase in self-awareness over this period was not associated with an increase in emotional distress.

An association between emotional distress and awareness has clinical significance. If an association does exist then we need to determine the causal relationship and consider how awareness should be addressed within rehabilitation programmes. Most studies appear to advocate an approach that focuses on the treatment of emotional distress and impaired awareness concurrently [9].

Various treatment strategies have been suggested to address impaired awareness. These include direct feedback, experiential feedback, education, and psychotherapy [8]. Feedback techniques allow for the provision of comments on individual performance during rehabilitation and naturalistic exercises. Education strategies focus on the provision of information about brain injury and it's ensuing consequences [43, 44]. Psychotherapy is intended to address the underlying adjustment issues [43]. These treatment methods are regarded as integral components of recognised neuropsychological rehabilitation programmes [8, 45]. There are however relatively few empirical studies that have investigated these strategies [20].

Chittum et al. [46] utilised a board game format to teach awareness to three adults with behavioural difficulties. They found that the participants were able to answer more questions correctly at the end of the programme and at follow-up periods, with some generalisation of the effect to novel questions. Youngjohn and Altman [47] described the use of direct feedback of cognitive performance to improve awareness in six adults with TBI. They found that the participants gave a more accurate prediction of their performance at the end of the intervention. They also observed that the participants verbalised some readjustment to their personal goals.

Case studies on the treatment of impaired awareness have also been published. Rebmann and Hannon [48] used feedback and positive reinforcement to improve awareness of memory deficits in three individuals with severe TBI. All three individuals showed an improvement in their ability to predict their performance on memory tasks. Using a similar approach Schlund [49] described the successful application of practice and performance feedback to improve awareness of memory functioning in an individual five years post TBI.

An exception to the small group or case methodology is the study of Ownsworth et al. [50]. They used a 16-week group programme involving components of cognitive rehabilitation, cognitive-behavioural therapy, and social skills training to improve self-awareness and psychosocial functioning in a group of 21 adults with ABI. Post-intervention and follow-up assessment revealed significantly improved levels of self-regulation, although self-awareness as measured by the SADI remained essentially unchanged. They reported that this was due to the already high level of pre-intervention intellectual awareness in their sample.

The published empirical studies on the treatment of impaired awareness appear to have focussed primarily on the methods of direct and experiential feedback with one that incorporated an educative component [51]. One method of feedback/education that has not been investigated empirically is the provision of information of brain scan findings. Computerised tomography (CT) and magnetic resonance imaging (MRI) are routine investigations following a neurological insult such as TBI or stroke [52, 53]. These images provide important information to medical doctors in the diagnosis and management of individuals in the acute stage of brain injury [53].

A brain scan image provides information on the location, size, and other aspects of the lesion or injury. This information can provide direction on the likely neurobehavioural outcome following brain injury [54]. For example severe traumatic brain injury may result in damage to frontal lobe structures with ensuing difficulties in executive and socio-behavioural functioning [1].

Brain scan findings have been reviewed with patients at the North Wales Brain Injury Service (NWBIS) and informal feedback suggests that they find this helpful and informative. Awareness can be limited by a lack of adequate knowledge about the consequences of ABI [26]. Allowing a patient to view their post-injury scan and explaining the findings presents an alternative feedback and education strategy. This process may assist individuals to restructure their knowledge and beliefs about themselves given that an ABI can affect the ability to experience problems accurately [7]. Flashman and McAllister [9] have noted that self-deception is likely to occur when there is a lack of concrete information. As such this approach provides a concrete and verifiable way of explaining post-injury changes to individuals.

The primary aim of this study was to investigate the effectiveness of feedback of brain-imaging findings as an intervention for improving awareness following ABI. For the purposes of this study impaired awareness was conceptualised as a discrepancy between patient and significant other rating on the AQ. In addition, the goal-setting section of the SADI provided an adjunct measure of self-awareness. Goal-setting ability has been described as an important dimension of self-awareness [20, 55].

In contrast to previous research this study also investigated the effect of the intervention on mood. All individuals participating in the intervention were in the post-acute stage of recovery. Given accounts suggesting that *persisting* impaired awareness may be associated with emotional distress [7, 39], it was hypothesised that an improvement in awareness post-intervention would be accompanied by a decrease in emotional distress. In contrast, a finding of higher levels of emotional distress following the intervention would be supportive of theories that link depression with increased awareness [33, 34]. Emotional distress was rated with self-report measures of depression and anxiety. Depression and anxiety states have been highlighted as important emotional sequelae following ABI [56, 57].

To date no studies have investigated the neuropsychological profiles of individuals who benefit from awareness interventions. Deficits in intellectual, executive or memory functioning may restrict an individual's capacity to understand, remember, and process knowledge of deficits [26]. This may in turn limit an individual's ability to benefit from a feedback intervention. This study explored the association between

benefiting from the intervention and executive, memory and general intellectual functioning. Standardised neuropsychological tests were utilised for this purpose.

Research into the relationship between awareness and factors such as depression and executive functioning have yielded mixed findings and further research is required in these areas. The study furthermore investigated the association between awareness and executive functioning and the association between awareness and mood.

Method

Participants

Participants were recruited from the NWBIS, a post-acute outpatient neurorehabilitation service in the United Kingdom. All participants were active patients of the NWBIS. A programme description of the NWBIS can be found in Coetzer et al. [58]. Senior clinicians referred individuals who had a suspected awareness problem. A total of 42 individuals were referred to the study. The selection criteria for inclusion were as follows: (1) diagnosis of moderate or severe TBI or cerebrovascular accident (CVA); (2) at least six months elapsed since ABI; and (3) the presence of a positive finding on brain imaging (CT and/or MRI). Potential participants were excluded if they: (1) had a pre-morbid diagnosis of a learning disability; (2) were currently receiving treatment for a substance misuse disorder; (3) had a severe psychiatric illness; or (4) were unable to communicate or see effectively. Eight persons were excluded on these grounds and four persons declined participation in the study. A total of 30 participants were selected for inclusion in the study. Demographic and injury-related variables for this sample are presented in table 1. Severity of ABI was established according to criteria as described by Guilmette [59].

>Insert table 1 about here<

The 30 participants were then assessed with awareness, neuropsychological, and mood measures. The primary purpose was to ascertain which participants had an awareness deficit as defined by an AQ discrepancy. Participants with an awareness deficit were included in the next phase of the study, i.e. the intervention phase. A total of 17 participants were included in the intervention phase. Six individuals were excluded as result of normal awareness measures (four point difference or less on the AQ), five individuals did not have scans readily available, one individual moved out of the area before the intervention, and one individual failed to attend the intervention appointment. Demographic and injury-related variables for the intervention sub-sample are also presented in table 1. Table 2 provides information on the time since injury, aetiology and lesion location(s) for each individual in this sub-sample.

>Insert table 2 about here<

Measures

Awareness measures:

Awareness Questionnaire [22]

The AQ measures self-awareness by asking patient, family member/significant other, and/or clinicians to rate the patient's abilities to perform various tasks after the injury as compared to before the injury. These are rated on a five-point scale ranging from "much worse" to "much better". The difference between the patient's ratings (AQ-P) and those of the family member/significant other (AQ-F) or clinician is considered to be a measure of impairment in self-awareness. Reliability studies of the AQ have revealed internal consistencies (Cronbach's α) of 0.88 for both patient and family

ratings [22]. For the purpose of this study the participant and a family member/ significant other completed applicable versions of the AQ. A difference score (AQ-D), indicating degree of impaired awareness was calculated by subtracting AQ-F from AQ-P.

Self-Awareness of Deficits Interview [20]

The SADI is a structured interview in which the examiner asks the individual specific questions related to self-awareness. The scale allows questioning in three areas: (1) self-awareness of deficit, (2) self-awareness of functional implications of deficit, and (3) ability to set realistic goals. Scoring is completed according to an established rating scale to determine level of self-awareness. Studies of the SADI have published interrater reliability [20, 60], test re-test reliability [61], and concurrent validity [62]. For the purpose of this study only the goal-setting section of the SADI was used. The reasons for this were as follows: (1) repeating the whole SADI three times in less than one month was considered too lengthy and cumbersome and (2) the goal-setting section provided an additional dimension of awareness not sampled by the AQ.

Measures of Depressed Mood:

Beck Depression Inventory – Second Edition (BDI-II) [63]

The BDI-II is a 21-item self-report instrument for measuring the severity of depression in adults. The BDI-II was developed for the assessment of symptoms corresponding to criteria for diagnosing depressive disorder listed in the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition [64]. The BDI-II has been utilised and researched for use in an acquired brain injury population [65-67].

The Hospital Anxiety and Depression Scale (HADS) [68]

The HADS was designed as a brief measure of anxiety and depression. It consists of two sub-scales, one measuring anxiety (HADS-A) and one measuring depression (HADS-D), which are scored separately. The HADS is a present-state instrument designed for use in medical hospital departments. It is applicable for repeated usage and may be administered at weekly intervals.

Neuropsychological Measures:

Executive measures

Wisconsin Card Sorting Test – Computerised Version 3 (WCST) [69]

The WCST provides a measure of flexible thinking and abstract reasoning ability. While some authors have reservations about the WCST it is considered by others as the 'gold standard' test of executive functioning and has been widely validated in lesioning and neuro-imaging studies [70]. The WCST provides measures of perseveration, conceptual level thinking, learning, and cognitive set maintenance. For the purpose of this study the 'trials to complete first category' score was used, providing a measure of initial comprehension and problem solving ability.

Tower Test [71]

The Tower Test is a stand-alone sub-test of the Delis Kaplan Executive Function System (DKEFS). The Tower Test measures several key executive functions including spatial planning, rule learning, inhibition of impulsive and perseverative responding, and establishing and maintaining the instructional set.

Verbal Fluency Test [71]

The Verbal Fluency Test is a stand-alone sub-test of the DKEFS that requires the oral production of spoken words beginning with a certain letter. It measures the speed and ease of verbal production. It evaluates ideational fluency and cognitive flexibility in a verbal format. It is sensitive to fronto-temporal involvement in general and left-frontal damage in particular [1].

Intellectual measure:

Wechsler Abbreviated Scale of Intelligence (WASI) [72]

The WASI is a brief, reliable means of assessing general intellectual functioning in clinical and research settings. The two sub-test version was used for this study.

Memory measures:

Logical Memory – Wechsler Memory Scales Third Edition (WMS-III) [73]

Logical Memory is a sub-test of the WMS-III. Logical memory consists of two parts and measures immediate and delayed verbal memory. A combined immediate and delayed verbal memory score was calculated for use in this study.

Faces – WMS-III [73]

Faces is a visual memory sub-test of the WMS-III. This sub-test uses a recognition paradigm to measure immediate and delayed memory. A combined immediate and delayed visual memory score was calculated for use in this study.

Procedure

General procedure

The initial sample of 30 participants were administered the awareness, mood, and neuropsychological measures. A family member/significant other completed the applicable version of the AQ during the initial assessment only. The findings of these assessments were utilised to investigate the association between (a) awareness and mood measures, and (b) awareness and executive measures. Those participants with an awareness deficit and an available brain scan (CT/MRI) indicating a positive finding (e.g. cerebral haemorrhage or contusion) were included in the intervention part of the study.

Intervention procedure

Participants were scheduled in to see a Consultant Neurologist (Co-investigator: R. Rafal) approximately two weeks after administering the psychological tests. During the consultation the neurologist conducted a review of the available brain scan/s with the participant according to the following protocol (An illustration of one consultation is provided in appendix B):

1. Neurologist will explain rationale and methodology of brain scanning: e.g. explain that CT scan is an X-ray, and that the image is based on density with air being black, and bone (i.e.) or blood being white. Ventricles are pointed out as being normal structures, depicting the density of water. Gray appearance of normal brain tissue is pointed out; and lesions like stroke or contusion are identified as regions of lower density than the normal surrounding brain.

2. Neurologist will point out the gross landmarks of the brain: lateral scout view is first inspected to orient the participant to the fact that each section depicts a slice of brain oriented approximately in the plane of the ear canal and corner of the eye. Obvious anatomic landmarks (e.g. eye balls, tip of nose) are pointed out to aid with orientation. Explain that brain is viewed from below with right side of brain on viewer's left. Major lobes of the brain are demonstrated with some comment on general function (e.g. occipital involvement in vision; temporal involvement in language and memory; frontal involvement in complex skills and personality)
3. Neurologist will explain pathological findings in lay terms
4. Neurologist will discuss possible neurobehavioural consequences
5. Neurologist will discuss any possible rehabilitation considerations
6. Opportunity will be given for participant to discuss findings/ask questions

The self-awareness measures and the clinical measures of mood were then repeated directly after the consultation. A follow-up assessment was conducted approximately 2 weeks after the consultation and self-awareness measures and mood measures were repeated.

A further analysis was conducted to determine whether there was an association between benefiting from the intervention (as measured by the decrease in AQ and SADI scores from baseline to follow-up assessment) and the neuropsychological measures.

Data Analysis Strategy

The statistical analysis was conducted using Statistical Package for Social Sciences (SPSS11.5V). Data for the initial sample was examined for missing variables. Seven percent missing data was found and mean replacements for this data were used. Outlying scores were substituted using the mean replacement method. Kolmogorov-Smirnov goodness of fit tests were conducted on all dependant variables. This revealed that normal distributions could be assumed for all but the SADI scores. Where appropriate non-parametric analyses were conducted with SADI scores. For the purposes of correlation analyses Bonferroni corrections were calculated and appropriate significance levels were established.

The relationship between the AQ and mood measures (HADS & BDI-II) was assessed with a Pearson Product Moment correlation. This was repeated for the test of the relationship between the AQ and executive tests. The association between the SADI and mood measures was assessed with a Spearman's rho correlation. This was repeated for the test of the relationship between the SADI and executive tests. Further correlation analyses were performed between the awareness and mood measures with the variable time-since-injury partialled out.

The outcome of the intervention on awareness measures and mood measures was assessed with one-way Repeated Measures Analyses of Variance (ANOVA) for three time points, namely baseline assessment, post-intervention, and follow-up. In addition effect sizes were calculated according to the recommendations of Cohen [74].

The relationship between benefiting from the intervention and neuropsychological measures was assessed with a Pearson Product Moment correlation and a Spearman's rho correlation.

Results

A summary of the baseline awareness, mood, and neuropsychological scores for the total sample (n=30) is presented in table 3. On the AQ participants rated their abilities an average of 7.67 (SD=7.35) points better than significant others, which equals an overestimation of 23.3%. The average SADI score was 1.2 (SD=0.85). According to the criteria described by Fleming [20], this suggests a moderate awareness problem. For the mood measures participants had an average HADS-A score of 8.5 (SD=4.42) representing mild anxiety, a HADS-D score of 6.03 (SD=4.15), which falls within the normal range, and an average BDI-II score of 15.83 (SD=9.92), which falls within the mild depression category. Care must however be exercised when interpreting BDI-II scores in an ABI sample as some items overlap with the biological consequences of brain injury [67].

>Insert table 3 about here<

Relationship between mood and awareness

The association between the mood and awareness measures is presented in tables 4 and 5. This analysis was performed with the total sample (n=30). No evidence of a relationship between mood (HADS-A, HADS-D, BDI-II) and awareness measures (AQ-D & SADI) was found. Due to a possible influence of the time elapsed since

injury, partial correlation analyses were performed to control for this variable. Controlling for time since injury did not change the results.

>Insert table 4 & 5 about here<

Relationship between executive functioning and awareness

These associations were investigated with the total sample (n=30). Pearson Product Moment and Spearman's rho correlations are presented in tables 6 and 7 respectively. No significant correlations were found between the AQ difference score (AQ-D) and executive measures. A correlation was found between the AQ difference score and the Tower Test ($p = 0.013$), this was however non-significant after Bonferroni corrections were applied. Spearman's rho correlations did not reveal any significant relationships between the SADI and measures of executive functioning. As with the AQ a correlation between the SADI and the Tower Test was found ($p = 0.008$), although this was non-significant after Bonferroni corrections were applied.

>Insert tables 6 and 7 about here<

Effect of intervention on awareness

Table 8 reports the results of the repeated measures ANOVA for the AQ (AQ-P) and SADI with the within subject factor represented by the measurement scores at baseline assessment, post-intervention, and follow-up. There was a significant pre- to post-test to follow-up difference on the AQ. For the SADI a significant difference was also found. The effect sizes were in the small to medium range [74].

>Insert table 8 about here<

Effect of intervention on mood

Table 9 presents the results of the repeated measures ANOVA for the HADS and the BDI-II with the within subject factor represented by the measurement scores at baseline assessment, post-intervention, and follow-up. The mean scores for the three mood measures decreased over assessment intervals. There was a significant pre- to post-test to follow-up difference for the BDI-II and the HADS-A. The change for the HADS-D was non-significant. The effect sizes for the BDI-II and for the HADS-A represented a moderate change.

>Insert table 9 about here<

Relationship between benefit and neuropsychological functioning

The difference between the baseline assessment and follow-up awareness scores served as indicators of the level of benefit from the intervention (AQ-C; SADI-C). Pearson Product Moment and Spearman's rho correlation analyses did not reveal a statistically significant association between benefit scores and indices of memory, executive, and intellectual functioning. Table 10 reports the results of the Spearman's rho correlations.

>Insert table 10 about here<

Discussion

The results of this study support the efficacy of the intervention for impaired awareness with a post-acute ABI sample. This finding supports previous studies that have found feedback and education to be beneficial methods to reduce aspects of impaired awareness following ABI [47, 49].

The size of the effect on the awareness measures was in the small to medium range, however given the nature of the instruments that were utilised this does not necessarily imply that the magnitude of the treatment effect was clinically meaningless. A small downward shift in scores on both the AQ and SADI may equate to a tangible improvement in awareness in the clinical context. For example the recognition of inappropriate goal setting may only reflect a one-point downward shift on the SADI but could result in the establishment of realistic goals that would significantly enhance the prospect of successful rehabilitation.

A possible explanation for the effectiveness of the intervention relates to the visual – tangible nature of the scan review process. Individuals with ABI often experience difficulty with higher-level conceptual thinking [1], and those with impaired awareness have difficulty with metacognitive processes such as self-reflection [7]. Very often individuals have been informed that they have suffered a brain injury for which they have no recollection or visible proof. Viewing their scans may provide a tangible reference to this traumatic event. Relating the impact of the brain injury to an actual visual representation may provide a more understandable approach for individuals with ABI to contextualise their deficits as opposed to returning the results of cognitive testing, which may be difficult to grasp.

An inspection of the mean awareness scores at the three assessment periods revealed that they were lowest directly after the intervention and increased slightly thereafter. This increase was not statistically significant but the question is raised as to whether a follow-up assessment more than two weeks from the intervention may have produced a different outcome. Future research would beneficially include a follow-up assessment that was at for example at six-months post intervention. This would allow for a more clinically relevant verdict on the utility of this procedure.

While the study demonstrated a change on awareness scores, an attempt was not made to determine if this finding generalised to more functional areas. Studies that incorporate a functional outcome measure of awareness would be advantageous in this respect. Prospective studies could also investigate the generalisation of treatment effects to real world functioning and the relationship of treatment gains to long-term outcome.

The study found that the intervention resulted in a reduction of mood scores on two measures (HADS-A, BDI-II). This effect was not found for the third measure (HADS-D), although a downward trend was observed. A reduction in mood scores occurred in concurrence with an increase in awareness scores. This finding supports theoretical explanations that implicate persisting impaired awareness in the manifestation of emotional distress [38, 39].

It is however not possible to definitively infer from this study that mood scores decreased as a direct result of an increase in awareness. An alternative, more conservative, way of conceptualising this finding is to state that the intervention did

not cause increased levels of anxiety and depression. As participants were more than twelve months post-injury, this finding indicates that for a post-acute sample increased awareness did not result in increased emotional distress. This finding supports the results of the study of Fleming et al. [42].

The results of this investigation did not support an association between impaired awareness and emotional distress even when time-since-injury was controlled for. The present study predominantly included participants in the chronic phase of ABI. It is possible that the relationship between awareness and mood may differ in the earlier stages of ABI [39]. A prospective study could investigate the association between awareness and mood in the sub-acute to post-acute phases of ABI.

A statistically significant association between impaired awareness and measures of executive functioning was not found in this study. This finding supports theories that suggest that awareness is a unique construct not sampled by traditional neuro-psychological measures [75]. Although not statistically significant, the Tower Test correlated with the SADI goal setting subsection. Goal setting involves the capacity for forethought and this would accord with a test that measures planning ability [71].

The results of this study did not support an association between benefiting from the intervention and neuropsychological functioning. This result suggests that the ability to benefit from the intervention did not depend on level of intellectual, memory, or executive functioning. No previous study has investigated this relationship and this aspect of the study was therefore explorative in nature.

This study had several limitations including the small sample size, the use of self-report questionnaires and the absence of a control group for the intervention. The sample size may have resulted in possible associations between variables, for example between awareness measures and executive measures, appearing as non-significant. Future studies could be designed to overcome these limitations.

Despite the limitations of the study the finding that impaired awareness decreased following the intervention was encouraging. The preliminary evidence suggests that it may have a valuable application in the clinical setting. This conclusion is supported by the finding that a positive effect was also observed on measures of depression and anxiety following the intervention. Feedback of brain scan findings may enhance rehabilitation outcome following brain injury.

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Appendix A. Tables

Appendix B. Illustration of intervention procedure

Feedback of brain scan findings: Brief illustration of the intervention procedure

Participant 14[1]

EM, a 52 year-old, left-handed man, suffered a traumatic brain injury following an industrial accident 4 years previously. His Glasgow Coma Scale score on admission to the Accident and Emergency Department was 5 and coma period was 2 weeks. He suffered multiple compound facial fractures, frontal lobe contusions and a right frontal lobectomy was later performed. EM lost the sight in his right eye and sustained burns to his left trunk and arm.

EM was referred to the North Wales Brain Injury Service for post-acute rehabilitation. He had significant neuropsychological and behavioural difficulties but denied that he had suffered a brain injury, reporting only that his vision and ability to use his left hand were affected. He did however cooperate with rehabilitation efforts. At baseline assessment EM stated that he wished to return to the same job that he had held previously. His AQ score was 37% higher in comparison to the relative version completed by his wife and his SADI goal-setting score was 2. A CT scan image for EM is presented in figure 1. This was taken prior to the neurosurgery.

> Insert Figure 1 about here <

The intervention session proceeded as follows:

EM was orientated to the CT scan according to the protocol described in the study. An anatomical model of the brain was on hand as an additional explanatory aid. EM was

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[1] Identifying demographic data have been obscured.

then shown how pieces of metal had struck him in the head and penetrated his skull and brain. The areas of the brain that were visibly affected by the injury were pointed out to him. A further post-surgery CT scan was shown to EM to illustrate how the lobectomy resulted in a loss of brain matter to the right frontal area. It was also pointed out to EM that the majority of his brain had a normal appearance.

The probable cognitive and neurobehavioural consequences of the injury were then discussed with EM. The main aspects highlighted included the following: EM was told that the scan results indicated that it was a severe brain injury and that there could be negative consequences for his thinking abilities and his interactions in social situations. He was told that there was a likelihood that he would have difficulty returning to the same work level he held before the injury. EM was also told that the consequences of the brain injury were likely to be permanent given that three years had elapsed since the injury.

Towards the end of the appointment EM commented that he had found the session informative and useful. He stated that this was the first time that he had seen his scans and it was helpful to see how the accident had injured his head. EM indicated during his post-intervention SADI interview that retirement was probably a reasonable idea and his score shifted down to 0. His AQ score however remained unchanged.

Appendix C. Figure 1

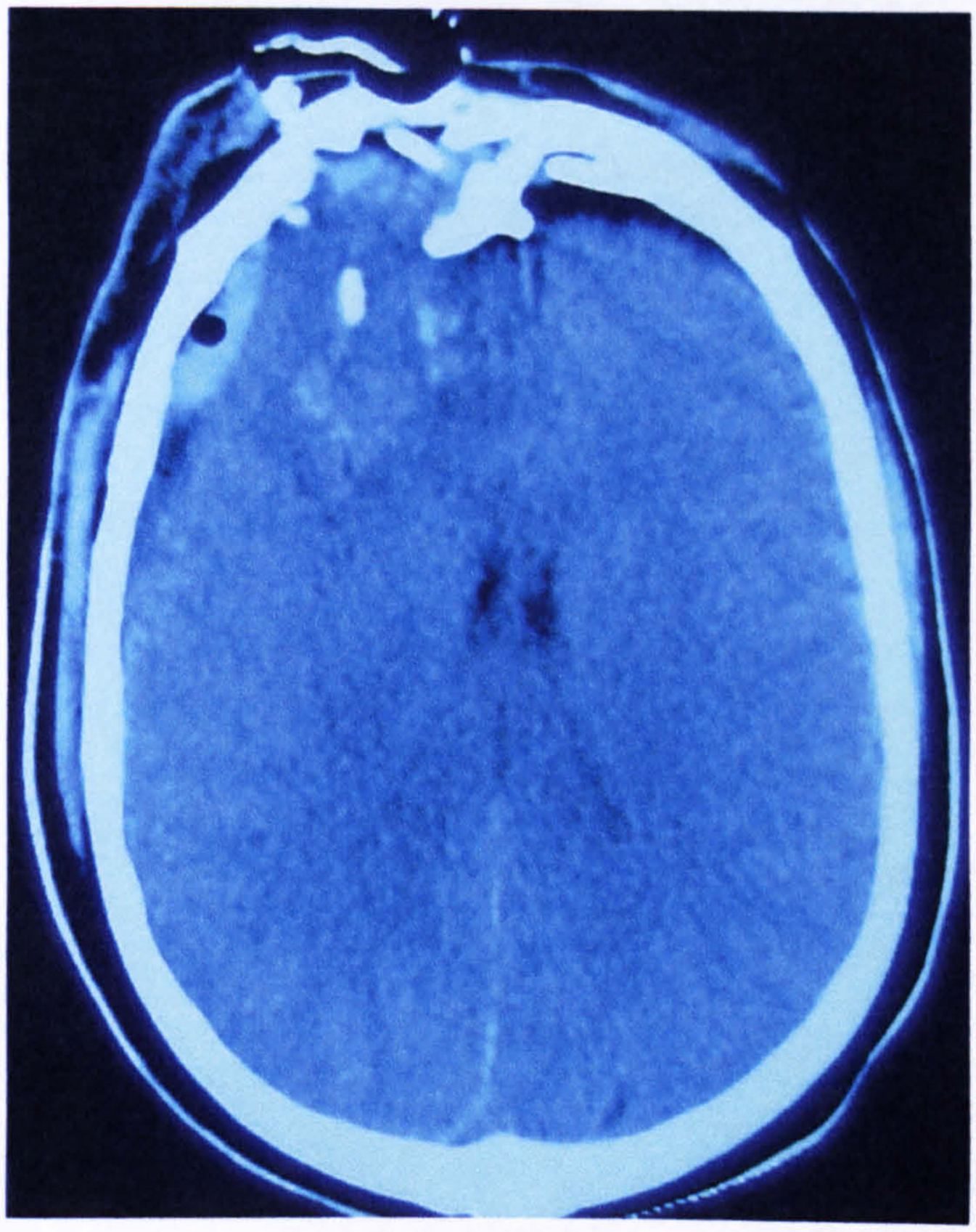

Figure 1: Axial CT - Participant 14

Appendix D. Instructions for authors : Brain Injury

SECTION 4. CONTRIBUTIONS TO THEORY, CLINICAL PRACTICE AND LEARNING

Contribution to theory, clinical practice and learning

Introduction and background

This study sought to examine the use of an intervention technique, namely reviewing brain scan findings with individuals who have impaired awareness following an acquired brain injury (ABI). The basis for the initiative arose out of everyday clinical practice at the North Wales Brain Injury Service (NWBIS). CT and MRI scans are usually held at tertiary medical facilities such as the Walton Centre for Neurology and Neurosurgery, Liverpool, where individuals were treated in the acute phase of their injury. Brain scan information is frequently requested at the NWBIS by the consultant neurologists in order to collate information on the extent and nature of the brain injury of individual patients. NWBIS clinicians consider this to be a valuable source of information to supplement assessments completed by clinical neuropsychologists, occupational therapists, physiotherapists and speech/language therapists.

Although brain imaging is primarily utilised as a diagnostic tool, the idea was conceptualised that it could also be used in a therapeutic manner. A CT or MRI scan essentially provides a photographic/x-ray image of the brain. Brain injury has been described as a hidden disability (Flashman & McAllister, 2002), given that for a large proportion of survivors the consequences are not obvious in the same way that, for example, an orthopaedic injury is. Being able to view an image of the brain provides a more tangible method of conceptualising the consequences of an ABI. The research question was thereby conceptualised as to whether impaired awareness in individuals with ABI could be successfully addressed by providing feedback of scan results.

While the focus of the study grew out of an interest in impaired awareness and the treatment thereof it was recognized that emotional factors such as depression play an equally important role in neurorehabilitation efforts. The relationship between awareness and depression has received significant attention in the literature (see Fleminger, Oliver, Williams, & Evans, 2003) and it was deemed an important additional aspect to explore in this study. Given the mixed empirical findings on the relationship between impaired awareness and neuropsychological functioning this association was also investigated in the study.

This study sought to investigate a novel approach to providing feedback to individuals with brain injury while also exploring the relationship between impaired awareness and associated variables. Attempting to answer these research questions can serve to enrich the field of clinical neuropsychology by broadening the scope of rehabilitation interventions and allowing for a better understanding of the impact of clinical phenomena on impaired awareness and visa versa.

Implications for future research and theory development

Feedback of brain scan findings as a treatment for impaired awareness

The primary objective of the study was to investigate the effectiveness of feedback of brain scan results as a treatment for impaired awareness. The findings of the study indicated that the intervention was relatively effective in this respect. This finding is encouraging given that it was a fairly novel approach. It suggests that the provision of relevant information in this format may be an important component in the amelioration of impaired awareness. This finding supports the theoretical position of

Crosson, Barco, Velozo et al. (1989) who propose that intellectual awareness can be limited by a lack of adequate knowledge about the consequences of ABI.

The intervention can best be described as a visual, tangible, and verifiable method of demonstrating the nature and possible consequences of an ABI. It may assist individuals to restructure their knowledge and beliefs about themselves given that an ABI can affect the ability to experience problems accurately (Toglia & Kirk, 2000). This method can be contrasted with the feedback of test results that may be more difficult for individuals with neuropsychological difficulties to grasp. Future research could compare different feedback intervention methods to examine this contention. For example feedback of brain scan results could be compared with feedback of neuropsychological test scores.

Dirette (2002) describes the development of deficit awareness as a slow process with occasional 'aha' moments occurring when an individual gains an important insight. The viewing of one's brain scan and appreciating the insult caused by the ABI may present an opportunity for such an 'aha' moment. Future research could adopt a qualitative approach to investigate the underlying psychological process individuals experience when viewing their scans and how this might foster awareness.

This study did not attempt to distinguish individuals with neurologically based impaired awareness from those with denial of disability related to underlying psychodynamic factors. Prigatano and Klonoff (1998) have delineated an approach to distinguish individuals with impaired self-awareness from those with denial of disability. Future research could compare these two groups in terms of their responses

to the scan feedback intervention. A qualitative approach would also provide valuable information on how individuals with impaired awareness compared to those with denial respond to viewing their scans.

Future research replicating the study needs to be undertaken with a control group. This would allow for firmer conclusions to be drawn about the actual mechanism at work. It would also be important to replicate the research with a larger sample. This would allow for a more productive investigation of factors that might predict which individuals benefit from the intervention.

Effect of the intervention on mood

The study found that measures of depression and anxiety decreased following the intervention. There are different of ways of conceptualising this finding each with consequences for future research and theory development. One explanation is that decreased emotional distress is a consequence of an improvement in awareness. This finding is consistent with the theoretical explanations of Prigatano (1997) and the findings of Ownsworth and Oei (1998). It supports explanations that suggest that individuals may become distressed when impaired awareness persists and they experience unexpected outcomes and failure (Toglia & Kirk, 2000). Further prospective research is needed to explore the association between an improvement in awareness and the effect on emotional distress.

A more conservative way of reporting this finding is to say that improved awareness did not result in an increase in depressed mood or anxiety. This finding does not accord with the account that proposes that improved awareness leads to depression

(Gainotti, 1993). It must be borne in mind that the sample studied were relatively long-term survivors of ABI with an average time since injury of 42 months. A different outcome may have been found if the sample were less than one-year post ABI, as it is during this period that individuals are first confronted with the consequences of their injury (Ownsworth & Oei, 1998). Further research is required with a sample less than one-year post ABI.

A second explanation for the finding that emotional distress decreased after the intervention is that the process itself accounted for a reduction in depression and anxiety levels. It is conceivable that the opportunity to meet with an experienced neurologist and to have scan results explained may have provided an opportunity for individuals to make better sense of a time in their lives for which they have little recollection. It may have given them the opportunity to contextualise confusing experiences such as the need for rehabilitation and repeated failures. This may have contributed to reduced emotional distress. A future study could investigate whether the process of reviewing one's scan benefits individuals with ABI who do not present with impaired awareness.

The association between awareness and mood

This study failed to find a correlation between baseline mood and awareness scores. The literature on the association between impaired awareness and mood has reported mixed findings and there is clearly a need for further research in this area. While cross-sectional designs have been used to examine the association between mood and awareness (e.g. Godfrey, Partridge, Knight, & Bishara, 1993) a prospective study

would be more appropriate to investigate this question. Contributing variables such as pre-morbid personality factors must also be considered in future investigations.

The association between awareness and measures of executive functioning

A secondary objective of this study was an investigation of the association between impaired awareness and executive functioning. No statistically significant associations were found between awareness measures and executive functioning. This finding is compatible with previous research that suggests that impaired awareness may be related to neuropsychological changes not measured by standard tests (Prigatano & Altman, 1990).

An inspection of the data did however reveal a trend towards one executive test being associated with both measures of awareness. The fact that this failed to achieve statistical significance may be due to the sample size used. A follow-up study with a significantly larger sample size is needed to investigate the association between awareness and executive functioning. If an association between executive functioning and awareness does exist, it would provide evidence to support theories that implicate deficient frontal lobe functioning in disorders of awareness (Stuss & Anderson, 2004).

Implications for clinical practice

The most significant clinical implication of this study was the finding that the provision of feedback of brain-imaging results can have a beneficial impact during the rehabilitation of individuals with ABI. Influential theoreticians and practitioners in the field have advocated the treatment of impaired awareness following brain injury (Ben-Yishay & Diller, 1993; Prigatano, 1999). This study has suggested a new

approach to the remediation of impaired awareness. It can be regarded as an approach that may supplement other methods of addressing impaired awareness.

Given that CT and MRI scans are regarded as diagnostic tools, this study showed that they could also be utilised in a therapeutic manner. Scans results can provide guidance on neurobehavioural outcome following ABI. Care must however be exercised when using brain-imaging findings to extrapolate cognitive and behavioural consequences of ABI (Bigler, 2001). The sole use of feedback of brain scan findings to predict outcome following ABI should be guarded against in the clinical setting. It can best be regarded as a supplemental approach to a range of feedback methods that already exist. It is proposed that other forms of outcome indicators such as the results of neuropsychological testing are combined with brain scan findings into a feedback approach. This method would appear to have a higher clinical utility than any single method in isolation.

Feedback of brain scan findings is an activity to be undertaken by appropriately trained medical doctors. Although clinical psychologists and neuropsychologists should not undertake this function there are potential clinically relevant implications to be noted for psychological practice. For example it is possible that feedback procedures that make use of visual and tangible explanations may be more successful than those based entirely on constructs such as the test scores for isolated cognitive functions. This assertion does however require proper empirical investigation.

The finding that the intervention resulted in a reduction of emotional distress has clinical significance. Williams and Evans (2003) have highlighted the importance of

addressing psychosocial factors following brain injury. Depression is a common consequence of ABI and therefore resources are required for the treatment thereof. Given the possible relationship between improved awareness and reduced emotional distress, the recognition of individuals with impaired awareness should be a standard activity within clinical practice and not just a research related pursuit.

The previous section highlighted the possibility that the intervention process itself may have served to lower depression and anxiety levels. If this hypothesis is correct then a case can be made to implement practices such as brain scan feedback sessions with all individuals participating in neurorehabilitation programmes. The feedback of scan findings can be conceptualised as a client-centred practice, as it gives individuals the opportunity to have access to all relevant information about themselves. This could be a useful addition to clinical practice.

The investigation of variables presumably associated with impaired awareness did not reveal significant correlations. There was however a trend suggesting an association between poor executive ability and impaired awareness. If an association does exist between executive functioning and impaired awareness then this may have clinical implications. For example, poor results on executive functioning measures could be an indicator that individuals have difficulty with the setting of realistic goals. This may alert clinicians to investigate the appropriateness of client goals.

This study provided evidence to support the assertion that impaired awareness is an important clinical phenomenon. Impaired awareness should be a key focus for clinicians within the rehabilitation environment.

Process/personal issues arising from the conduct of the research

This research was completed as part of the DClinPsy degree for "partially qualified candidates" (PQC). This is a training scheme offered by the University of Wales, Bangor for individuals who have, for example, received their clinical qualification in a different country (as was the case for this investigator). Participating in this training scheme presented both advantages and challenges for the research process.

One benefit was that the research was formulated and conducted within the place of work where the investigator was employed on a full-time basis (NWBIS). This aided the process of developing the research question. For example, it was possible to work with the neurologist and observe the process of providing feedback of scan results to clients prior to the formulation of the research proposal. The research hypothesis was consequently developed in relation to relevant aspects of clinical practice. It also gave the opportunity for an appraisal of what could be achieved within the scope of the research project. Without the benefit of this knowledge the investigator could have struggled with the recruitment of participants by formulating a research question that was not achievable within clinical and time constraints.

The main challenge in conducting research under the PQC system concerned an obvious issue regarding time restrictions. Being employed on a full-time basis, and having to complete other requirements for the DClinPsy degree, left little time to plan and execute the research. A consequence of this was that the research process had to be condensed into a time period following the completion of the other degree requirements. This prevented aspects of research such as a pilot study being carried

out. A pilot study would have been particularly beneficial to this study given the relatively novel nature of the intervention. This would have allowed for a refinement of the intervention procedure.

The design and implementation of the feedback procedure resulted in notable process issues. The completion of this study was dependent on the collaboration of a co-investigator as the intervention was required to be performed by a neurologist. The co-investigator was fully invested in the study and provided his time generously. This study did however require two persons with differing professional backgrounds to design and implement an untested feedback procedure. This consequently necessitated discussions on the scientific and psychological merits of the study. This process was challenging but provided a valuable insight into the philosophical orientation of an individual from a different professional background.

A significant challenge was encountered during the ethics application process. The national system of ethical approval for research conducted within the National Health Service has recently undergone a transformation. A centralised office for research ethics committees was established in 2003/2004 and new procedures were instituted for the approval of research projects. Unfortunately the present study's ethical and research governance (R&D) application was submitted while these changes were being implemented. This led to a situation where no clear guidance was available on how to proceed and ultimately led to a three-month delay in receiving final approval for commencement of the study.

This study presented an opportunity to conduct research with a population that the investigator usually sees for clinical reasons. It proved to be an enlightening experience as it placed the investigator in a different relationship with persons who would normally be requesting assistance. In this case the roles were reversed and based on their informal feedback it appeared that the participants gained a sense of meaning by offering their time and assistance to the project. This ultimately gave the investigator the impression that the participants were more research 'collaborators' than research 'subjects'

The research was however not without ethical considerations. As described throughout the thesis, researchers have hypothesised a potential association between increased awareness of deficits and the onset of depression. The procedure essentially entailed showing participants the damage inflicted to their brain. This process could be perceived as showing individuals 'what is wrong with them' and 'what they have lost'. There was a concern that providing feedback of brain imaging results to individuals with impaired awareness could culminate in the development of a grief or depressive reaction. Current theory however appears to allay this concern by contending that the process of adaptation following a traumatic event hinges on understanding the loss (Davis & Nolen-Hoeksema, 2001). For the investigator, the concept of withholding information from individuals is incongruous with the philosophy of a person-centred approach that advocates genuineness and honesty within a therapeutic relationship (Rogers, 1961). The possibility of increased emotional distress was nonetheless stated explicitly in all documentation provided to the ethics committees and participants. The eventual findings of the study did not support this initial concern.

This study provided the investigator a glimpse into the phenomenological experience of individuals who struggle to comprehend the complete and complex nature of the neurological insult that has befallen them. What struck the investigator most was how debilitating and confusing this condition can be for these individuals and how frustrating for those who are closest to them. Studying impaired awareness from this personal perspective can deliver valuable insights for a practising clinician.

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SECTION 5. MAIN APPENDICES

Appendix A. Ethics approval from School of Psychology

Ysgol Seicoleg
Prifysgol Cymru, Bangor

Adeilad Brigantia, Ffordd Penrallt
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February 6, 2004

Dr. B.R.Coetzer, Mr. C.B.Roberts
North Wales Brain Injury Service
Colwyn Bay Community Hospital
Hesketh Road
Colwyn Bay
LL29 8AY

Dear Colleagues

Feedback of Brain Scan Findings: effect on self-awareness

Your research proposal (referred to above and on the attached sheet) has been reviewed by the School of Psychology Research Ethics Committee and they are satisfied that the research proposed accords with the relevant ethical guidelines. If you wish to make any substantial modifications to the research project please inform the committee in writing before proceeding. Please also inform the committee as soon as possible if research participants experience any unanticipated harm as a result of participating in your research.

You should now forward the proposal to the appropriate Research Ethics Committees of the North Wales Health Authority. They expect one of the investigators to make an oral presentation in support of the proposal at their meeting. You will be contacted by their committee with details as to the date and place of the meeting at which your proposal will be considered.

You may not proceed with the research project until you are notified of the approval of the NWHA research ethics committee.

Yours sincerely

Kath Chitty
Coordinator - School of Psychology Research Ethics Committee

C Fergus Lowe PhD, FBPsS
Athro a Phennaeth yr Ysgol • Professor and Head of School

Appendix B. Ethics approval from North East Ethics Committee

Pwyllgor Moeseg Ymchwil Dwyrain Gogleddd Cymru
North East Wales Local Research Ethics Committee

Cydlynydd Moeseg
Ethics Co-ordinator
Ysbyty Maelor Wrecsam/Wrexham Maelor Hospital
Croesnewydd Road
Wrecsam/Wrexham
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Llyth-el/E-mail: Eleanor.Thomas@new-tr.wales.nhs.uk

Mr C B Roberts
Clinical Neuropsychologist
North Wales Brain Injury Service
Colwyn Bay Community Hospital
Hesketh Road
Colwyn Bay
Conway
LL29 8AY

17 MAR 2004

15 March 2004

Dear Mr Roberts

Full title of study: Standardised Clinician Feedback of Brain Scan Findings – Effect on Impaired Self-Awareness and Mood in Acquired Brain Injury
REC reference number: Roberts/Feb 04

The Sub-Committee of the North East Wales Local Research Ethics Committee reviewed the above application at the meeting held on 11 March 2004

Ethical opinion

The Sub-Committee was pleased with the requested amendments to the patient Information Sheet, and are happy to give full approval for the study to proceed

The members of the Committee present gave a favourable ethical opinion to the above research on the basis described in the application form, protocol and supporting documentation.

Approval is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

Standard letters version 5 dated 20 January 2004
SL6 Favourable opinion at first review

AMENDMENTS
Dated: 09/03/2004
Date Received: 09/03/2004

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Communication with sponsor and host organisations

This letter is confidential but we shall notify the sponsor (and host organisation if appropriate) of the outcome of the review.

Statement of compliance ***(from 1 May 2004)***

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees in the UK and complies fully with national standard operating procedures.

Yours sincerely,

Miss Eleanor Thomas
Research Ethics Co-ordinator
North East Wales LREC

Enclosures *List of names and professions of members who were present at the meeting or who submitted written comments*
Standard approval conditions

List of names and professions of members who were present at the meeting or who submitted written comments

Dr P Rutherford – Chairman
(Medical Director)

Mr P Richards – Vice Chair
(Associate Specialist – Surgery)

Eleanor Thomas – Administrator
(Research Ethics Co-ordinator)

Appendix C. Research governance approval

17 JUN 2004

Ymddiriedolaeth GIG Siroedd Conwy a Dinbych
Conwy & Denbighshire NHS Trust

TO: Mr Craig B Roberts
Clinical Neuropsychologist
North Wales Brain Injury Service
Colwyn Bay Community Hospital
Hesketh Road
Colwyn Bay

Ein cyf/Our ref: LTJ/March/2004
Eich cyf/Your ref:
Dyddiad/Date: 15 June 2004
Wrth ffonio gofynnwch am/if telephoning ask for
Lona Tudor Jones
Llinell Uniongyrchol/Direct Line:
01745 – 589624
E-Mail Address
Lona.TudorJones@cd-tr.wales.nhs.uk

Dear Mr Roberts

Re : Trust Approval to Proceed

Project: Standardised clinician feedback of brain scan findings - effect on impaired self-awareness and mood in acquired brain injury

Trust Ref: 2004/Psych/170

Your project was discussed at the Internal Review Panel for the Conwy and Denbighshire NHS Trust on 15 June 2004. I am pleased to inform you that your project obtained approval to proceed.

As part of regular monitoring undertaken by the Trust R&D Committee, you will be required to complete a short progress report. This will be requested on a six monthly basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Trust is keen to reduce the burden of paperwork for Researchers failure to produce a progress report may result in withdrawal of approval and any allocated funding. To confirm the details and amount of funding, if any, allocated to your project, please contact Shelagh Evans, in the Finance Dept at H M Stanley Hospital. Ext: 3771.

All research conducted at Conwy and Denbighshire NHS Trust must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trust's R&D webpages. Alternatively you may obtain a paper copy of this document via the Trust R&D Office.

I trust this is in order. If you would like further information on any of the points covered by this letter, please do not hesitate to contact me. On behalf of the R&D Committee, may I wish you every success with your research.

Yours sincerely

Lona Tudor Jones

Lona Tudor Jones
R&D Manager

Cc Ethics Administrator

Appendix D. Statement of word count

Word counts for papers

Summary of thesis

Title:	11 words
Abstract:	222 words

Ethics proposal

Main text:	3207 words
References:	278 words
Total:	3485 words

Literature review

Abstract page:	118 words
References:	2876 words
Main text:	7322 words
Total:	10316 words

Research paper

Abstract page:	140 words
References:	1789 words
Main text:	5049 words
Total:	6978 words

Discussion paper

References:	382 words
Main text:	2877 words
Total:	3259 words

Thesis total

Ethics proposal:	3207 words
Literature review:	7440 words
Research paper:	5189 words
Discussion paper:	2877 words
Total:	18713 words

References and appendices

References:	5325 words
Appendices:	3036 words
Total:	8361 words