Well-being in Clinical Neuroscience Settings

A thesis submitted to the University of Manchester for the degree of
Doctorate in Clinical Psychology
In the Faculty of Medical and Human Sciences

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Andrew James Leigh

School of Psychological Sciences
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<td>ACE-R</td>
<td>Addenbrooke’s Cognitive Examination - Revised</td>
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<td>BCC</td>
<td>Behaviour Category Code</td>
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<td>DCM</td>
<td>Dementia Care Mapping</td>
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<td>DCM-NR</td>
<td>Care Mapping – Neurorehabilitation</td>
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<td>GCS</td>
<td>Glasgow Coma Scale</td>
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<td>LOC</td>
<td>Loss of consciousness</td>
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<tr>
<td>ME value</td>
<td>Mood and engagement value</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini-mental State Evaluation</td>
</tr>
<tr>
<td>NPDS</td>
<td>Northwick Park Dependency Scale</td>
</tr>
<tr>
<td>PCC</td>
<td>Person-centred care</td>
</tr>
<tr>
<td>PPE</td>
<td>Potential for positive engagement</td>
</tr>
<tr>
<td>PTA</td>
<td>Post-traumatic amnesia</td>
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<tr>
<td>QoL</td>
<td>Quality of Life</td>
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<td>TBI</td>
<td>Traumatic Brain Injury</td>
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<td>WIB score</td>
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Abstract
The University of Manchester
Andrew James Leigh
Doctorate of Clinical Psychology, ClinPsyD

Well-being in Clinical Neuroscience Settings

June 2013

The aim of this thesis was to investigate the well-being of patients in clinical neuroscience settings. Both the systematic review and research papers are being prepared for submission to the journal of Neuropsychological Rehabilitation, the guidelines of which are included in the appendices (Appendix 1).

Paper one is a systematic review of the literature investigating the prevalence of depression following traumatic brain injury (TBI). 26 papers were reviewed with 15 meeting quality assessment criteria and were described in further detail. The prevalence of depression following TBI, reported in the reviewed studies, varied between 19% and 46%. The quality of the methodology of the studies is evaluated and discussed.

The research paper (paper two) investigated the relationship between well-being, cognitive impairment and dependency using care mapping-neurorehabilitation (DCM-NR) as a measure of well-being. This study applied DCM-NR in a range of clinical neuroscience settings. Participants considered to have severe cognitive impairment were found to have significantly lower well-being (as measured by DCM-NR), and to be more dependent than participants with moderate, mild or no cognitive impairment. Overall level of dependency and cognitive impairment accounted for 23.9% of the variance in well-being scores from the DCM-NR.

Paper three is a critical appraisal of the systematic review and research paper. Pertinent issues, including methodological limitations, relevant to the two papers are discussed in addition to clinical and research considerations.
Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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I would also like to thank my friend, Ambu for reading through the drafts of this thesis and offering his insights.

I am particularly grateful to my fiancée and family for their understanding and unwavering support over the years, without them this would not be possible.
Depression after Traumatic Brain Injury: A Systematic Review

A.J. Leigh\textsuperscript{1}, R. Sheldrick\textsuperscript{1,2}, D.J. Hare\textsuperscript{1}

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Paper one word count: 5308

1 Department of Clinical Psychology, University of Manchester, Manchester, UK
2 Department of Neuropsychology, Salford Royal, Salford, UK
Abstract

**Background:** Traumatic brain injury (TBI) is recognised as having a detrimental impact on the individual, of which depression is a well acknowledged consequence. However, there is a paucity of accurate prevalence data of depression after TBI, and there is a need for clarification of the evidence for depression following a TBI (Kreutzer, Seel & Gourley, 2001).

**Method:** A systematic review of MEDLINE and PsychINFO databases returned 363 studies of which 26 were appropriate for review. A quality assessment tool was devised and 15 studies were considered to adequately answer the aim of this review.

**Results:** Prevalence rates of depression following TBI in the majority of studies ranged from 19% to 46%. Studies employed a range of self-report and diagnostic tools in measuring depression, but consistently used GCS or PTA in determining the severity of TBI.

**Conclusions:** TBI presents frequently and depression is one of the main consequences with significant clinical implications. The variety of tools used to measure depression made comparing prevalence data across studies problematic, highlighting the need to develop a standard measure of depression after TBI.

**Keywords:** brain injury, depression, systematic review, traumatic brain injury, TBI.
Introduction

The impact of Traumatic Brain Injury (TBI) on the individuals who suffer them, and on society, cannot be overstated. In a systematic review of the literature, Tagliaferri et al. (2006) calculated the incidence of TBI in Europe to be 235/100,000 per annum and the mortality rate to be at 15/100,000 per annum. Furthermore, TBI is estimated to cost the US economy approximately $48.3 Billion (Reilly, 2007) and the Australian economy $8.6 Billion each year (Access Economics, 2009). Traumatic Brain Injury is recognised as the leading cause of disability in those under 40 years of age (Fleminger & Ponsford, 2007) and the World Health Organisation predict that TBI will surpass many other diseases to become the leading cause of disability and mortality worldwide (Hyder et al. 2007).

A number of researchers have described the range of cognitive, physical and emotional sequelae of TBI (Bay et al. 2009; Draper et al. 2007; Finset & Andersson, 2000; Ownsworth et al. 2011). These consequences have a significant negative impact on family and social functioning in everyday life (Anson & Ponsford, 2006; Draper et al. 2007; Martin et al. 2001). Occupational and social limitations are common, with unemployment rates recorded to be between 10 and 70% (McCrimmon & Oddy, 2006). All these factors have a negative impact on the Quality of Life (QoL) for individuals following a TBI (Vickery, Gontkovsky & Caroselli, 2005), with Andelic et al. (2009) noting reduced QoL 10 years after injury, compared with the general population.

Disability can arise from any cognitive, physical, emotional and psychological factors (Holsinger et al. 2002); however, most current research has focused on the emotional and psychological problems common in people following TBI (Martin et al. 2001). Research in this area has identified increased rates of psychological morbidity in TBI, specifically anxiety disorders (Moore, Terryberry-Spohr & Hope, 2006) including; Post-Traumatic Stress Disorder, aggressive behaviour, suicide and psychosis (Hesdorffer, Rauch & Tamminga, 2009). There are considerable amounts of research evidence supporting depression as being a common problem for people following TBI (Bay et al. 2009; Glenn et al. 2000; Hibbard et al. 2004; Hudak et al. 2012; Kreutzer et al. 2000; Kreutzer, Seel & Gourley, 2001;).

A recent systematic review by Waraich et al. (2004) reported the pooled prevalence of depression in the general adult population to be 4.1%. Depression is thought to be the most common psychiatric diagnosis amongst people who have had a TBI (Hart et al. 2012) with prevalence rates ranging from 6 to 77% of cases (Franulic, et al. 2004). However, there is inherent difficulty in measuring depression following TBI as many
depressive symptoms such as increased fatigue, apathy and reduction in concentration and attention (DSM-IV: APA, 2000), among others, are also common direct consequences of a TBI without depression (Kreutzer et al. 2001). A review of the research into mild TBI and depression by Busch and Alpern (1998) found depressive symptoms in approximately 35% of people following mild TBI. There is a large degree of overlap in symptomology of Major Depressive Disorder (DSM-IV: APA 2000) and post-concussive syndrome (PCS), a collective term for symptoms seen shortly after a mild TBI. This overlap was cited as one of the difficulties with accurately determining the prevalence of depression after a mild TBI.

Understanding depression following TBI is further complicated by the heterogeneity in its conceptualisation. Depression following TBI is viewed as both a patho-physiological consequence of TBI and as a disturbance in psychosocial adjustment post-TBI (Malec et al. 2007; Moldover, Goldberg & Prout, 2004), reflecting the dissonance between the psychiatric/medical and psychological models of depression in the literature.

Research into factors influencing development of depression following TBI has shown females to have worse mental health following TBI than males (Andelic et al. 2009) and are more likely to report depression symptoms (Bay et al. 2009). Despite the paucity of research in the area of cultural differences in depression after TBI, a recent American study found that there are differences in symptom reporting, with Hispanics reporting higher levels of depression than White or African Americans, between which there was no difference (Aranga-Lasprilla et al. 2012). Other factors that influence depression following TBI include employment and coping strategies (Anson et al. 2006; Curran, Ponsford & Crowe, 2000) but not injury severity or time since injury (Hibbard et al. 2004; Malec et al. 2007).

It is established that depression following TBI has wide ranging and profound consequences for the individual’s QoL (Vickery, Gontkovsky & Caroselli, 2005). Seel et al. (2003) demonstrated that depression exacerbates cognitive problems following TBI. Returning to gainful employment is a good indicator and goal of successful rehabilitation; however, depression has been shown to complicate returning to work following TBI (Franulic et al, 2004; McCrimmon & Oddy, 2006).

At present, there is an unclear relationship between depression and poor functional outcomes. Schonberger et al. (2011) argued that decreased functioning led to the development of depression; whereas, Hudak et al (2012) found that depressed patients engaged less with rehabilitation, resulting in poorer functional outcome.
Nevertheless, the effects of psychological and cognitive impairments are often the most difficult for the individual to accept following a TBI (Franulic et al. 2004).

Researchers have reviewed past literature into depression following TBI. Busch and Alpern (1998) only reviewed studies involving mild traumatic brain injury, and while Morton and Wehman (1995) reviewed studies across the range of TBI severity, both reviews were conducted on literature greater than 15 years old. There has been a single systematic review that focused exclusively on depression after TBI in the elderly (Menzel, 2008). Given that there hasn’t been a recent review into depression following TBI there is a need for an up-to-date review of the existing research.

In addition to this primary aim a number of specific questions were considered:

- What explanations may exist for the large variance in reported prevalence rates of depression in people with TBI, such as demographic factors, severity of injury or time since injury.
- Are some measures of depression more accurate than others at measuring depression in TBI

Rationale and Aim

To date no systematic review of the evidence base regarding depression following TBI has been conducted in the general adult population. The aim of this review was to clarify and describe recent research into depression following TBI by conducting a systematic review of the literature.

Method

Search Strategy

A systematic review of the relevant literature was conducted by searching the MEDLINE (1946 to December 2012) and PsycINFO (1806 to December 2012) databases. The search terms used were Brain Injury/Injuries and Depression; which returned 363 articles. The following limits were imposed upon the results from this search: Human studies, English language, and published in a peer reviewed journal between 1995 and 2012.
Selection Criteria

Of the 250 articles that remained, a manual search of the results was conducted and only studies that fulfilled the inclusion/exclusion criteria were retained. Studies were excluded if they (1) investigated mild head injury or post-concussive syndrome only, (2) were looking at brain injury in children, (3) were studies looking at treatment of depression following brain injury, and (4) if they were case series/case study.

Following the removal of duplicate studies, studies were only included in the research if: (1) a validated measure of depression was utilised and (2) depression outcome was reported. The inclusion of a control or comparison group was not considered to be required criteria.

Search Results

Following the application of the inclusion and exclusion criteria, 215 articles were excluded on the basis of their title and/or abstract. The predominant reasons for exclusion were investigation of mild head injury or post-concussive syndrome only and lack of a validated measure of depression. Following review of the entire article, 25 studies were included. Studies were required to report data on the prevalence of depression or depressive symptoms.

All reference sections, of the included papers, were screened to identify relevant studies, and one suitable study was integrated in this way. Therefore a total of 26 studies were included for the purposes of this systematic review.
Quality Assessment

As there is currently no single consensus tool for data extraction and quality assessment of epidemiological studies (Sanderson, Tatt & Higgins, 2007), data was extracted and assessed based on the recommendations of the aforementioned review,
The quality assessment tool was devised by the authors specifically for use in this review. The criteria used to score each study were as follows:

- **Design**: A study was scored 2 points if it was of a prospective or retrospective cohort design. It was scored 1 point if it was of cross-sectional design and 0 if the study was of a case control or indeterminate design.

- **Recruitment**: A study was scored 2 points if it recruited from multiple sites or 1 point if recruitment was from a single site and 0 points if recruitment site was not stated.

- **Sampling**: A study was given 1 point if it attempted to reduce sampling bias through consecutive, random, or matched sampling; otherwise it was scored 0 points. Studies using existing databases were scored as above, depending on whether the existing database had attempted to reduce sampling bias.

- **Sample Size**: A study scored 1 point if the sample size was appropriate for the study design (N>50 for Cross sectional designs, and N>100 for cohort designs).

- **Control Group**: A study was scored 1 point if it employed a control or comparison group and 0 if it did not.

- **TBI Measure**: A study was scored 1 point if it reported the measure used to determine TBI severity and another 1 point was given if the distribution of TBI severity was reported.

- **Depression Measure**: A study was scored 2 points if it used an objective measure of depression, such as BDI or HADS; a study was scored 1 point if it used a subjective measure of depression.

- **Time Point**: A study was scored 1 point if it reported appropriate information describing the time since injury for the sample.

- **Statistics**: A study was given 1 point if it reported comparative statistics and 0 points if it reported descriptive statistics only.

Inter-rater reliability, based on three randomly chosen studies, was determined to be adequate with a greater than 80% agreement. Consultation with one or more researchers was sought where ambiguity of scoring was identified.
Results

Definition of terms for Table 1.
NR= Not recorded in article

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<tr>
<th>Design</th>
<th>TBI Measure</th>
<th>Time since injury in months</th>
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<tr>
<td>PC=Prospective Cohort Design</td>
<td>PTA= Post Traumatic Amnesia</td>
<td>IP-Inpatient</td>
</tr>
<tr>
<td>RC=Retrospective Cohort Design (2/2)</td>
<td>GCS= Glasgow Coma Scale</td>
<td></td>
</tr>
<tr>
<td>XS=Cross Sectional Design (1/2)</td>
<td>LOC= Loss of Consciousness (All 1/1)</td>
<td>Time since injury reported (1/1)</td>
</tr>
<tr>
<td>CC=Case Control Design (0/2)</td>
<td>% Moderate, % Severe TBI (1/1)</td>
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<tr>
<th>Recruitment (Sampling):</th>
<th>Depression Measure</th>
<th>Statistics</th>
</tr>
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<tr>
<td>MS=Multiple or Major Sites (2/2)</td>
<td>Objective measure of depression symptoms</td>
<td>C=Comparative (1/1)</td>
</tr>
<tr>
<td>SS=Single site (1/2) &amp;</td>
<td>e.g. validated measure (2/2)</td>
<td>D=Descriptive (0/1)</td>
</tr>
<tr>
<td>CS=consecutive sampling</td>
<td>Subjective measure of depression symptoms</td>
<td></td>
</tr>
<tr>
<td>RS= Random Sampling</td>
<td>e.g. clinical diagnosis (1/2)</td>
<td></td>
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<tr>
<td>ED= existing database (e.g TBIMS)(All 1/1)</td>
<td>No validated measure of depression symptoms or self-report. (0/1)</td>
<td>Maximum score = 13</td>
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<td></td>
<td></td>
<td>Upper tertile = &gt;9</td>
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<th>Study</th>
<th>Study Aim</th>
<th>Design 0/2</th>
<th>Recruitment 0/3</th>
<th>Sample Size (control) 0/2</th>
<th>TBI Measure 0/2</th>
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<th>Statistics 0/1</th>
<th>Summary of Findings 0/13</th>
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<td>2. Hart et al. 2012</td>
<td>Patterns of change in depression 1-2 years post-TBI</td>
<td>PC</td>
<td>MS</td>
<td>1089</td>
<td>All moderate or above</td>
<td>OM (PHQ-9)</td>
<td>12-24</td>
<td>C</td>
<td>26% of those not depressed 1 year after TBI developed depression. Worse levels of depression at year 1 are associated with higher odds of clinically significant depression 1 year afterwards. Score =10</td>
</tr>
<tr>
<td></td>
<td>Authors</td>
<td>Research Question</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Outcome Measures</td>
<td>Findings</td>
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<td>4.</td>
<td>Hudak et al. (2012)</td>
<td>Functional ability correlate with depression post-TBI</td>
<td>RC 2, MS 2, NR 1, 471</td>
<td>GCS 2</td>
<td>OM, (BDI-II) 1% 6-12 D</td>
<td>Higher BDI-II scores correlated with lower Functional Status examination scores. 12% of the mild-TBI group scored above cut-off (18) for depression and 1% of moderate-severe TBI (&gt;34)</td>
<td></td>
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<tr>
<td>7.</td>
<td>Ownsworth et al. (2011)</td>
<td>Investigate the link between Depression, perceived functioning and transition events</td>
<td>PC 2, MS 3, CS 0, 96</td>
<td>PTA &amp; GCS 2</td>
<td>OM (DASS) 24% at discharge, 27% at 3 months 1 1 0-3 C</td>
<td>Depressive symptoms were in the normal range at discharge and at 3months. 47% perceived their functioning to be a little worse. Total transition events predicted DASS-21 score at 3 months. Perceived functioning mediated total transition events and DASS-21 score.</td>
<td></td>
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<td>8.</td>
<td>Whelan-Goodinson et al. (2010)</td>
<td>Investigate predictors of psychiatric diagnoses following TBI</td>
<td>RC 2, SS 2, RS 1, 100</td>
<td>GCS &amp; PTA 2</td>
<td>SM (SCID) 46% 12-60 C</td>
<td>Gender, Presence of Pain, Post Injury employment, pre-injury depression, years of education and time post-injury were significant predictors for post-injury depression. Post injury employment, pre-injury anxiety and age are significant predictors of post-injury anxiety.</td>
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<td>9.</td>
<td>Malec et al. (2010)</td>
<td>To develop and evaluate a post-TBI depression model</td>
<td>XS SS CS 158 None</td>
<td>PTA, 46% &gt;Severe</td>
<td>OM (BDI-II) 30% mild 10% moderate - severe IP C</td>
<td>Depression and injury severity were not correlated; however, self-appraisal of ability was found to correlate with depression.</td>
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<tr>
<td>10. Weddell (2010)</td>
<td>Determine relationship between depression &amp; relative reactions on outcome</td>
<td>RC</td>
<td>SS</td>
<td>78</td>
<td>GCS &amp; PTA</td>
<td>OM (ZDS)</td>
<td>M = 34.3, SD = 15.2</td>
<td>C</td>
<td>Critical Comment scores from family were associated with participant's reactions and outcome after controlling for TBI severity and social class. Rate of depression increased over time in the high Critical comment group. <strong>Score = 10</strong></td>
</tr>
<tr>
<td>12. Andelic et al. (2009)</td>
<td>Determine functional outcome and health-related quality of life 10 years after TBI.</td>
<td>RC</td>
<td>SS</td>
<td>62</td>
<td>GCS</td>
<td>OM (BDI)</td>
<td>120</td>
<td>C</td>
<td>Majority of patients had moderate disability (44%) or good recovery (48%), had returned to employment (58%) and both were related to injury severity and not health-related quality of life. Frequency of depression was 31%, and for epilepsy was 19%. <strong>Score = 9</strong></td>
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<tr>
<td>13. Draper et al. (2007)</td>
<td>Examine psychosocial outcome and its demographic factors 10 years after TBI.</td>
<td>RC</td>
<td>SS</td>
<td>53</td>
<td>PTA</td>
<td>OM (HADS)</td>
<td>120</td>
<td>C</td>
<td>Aggression, anxiety, depression, length of education, fatigue, and TBI severity were significantly associated with psychosocial outcome. Of these length of PTA, depression, anxiety and aggression were most strongly associated with outcome. <strong>Score = 9</strong></td>
</tr>
<tr>
<td>14. Malec et al. (2007)</td>
<td>Investigate and describe the factors affecting depression after TBI.</td>
<td>NR</td>
<td>NR</td>
<td>135</td>
<td>GCS</td>
<td>OM (NFI)</td>
<td>0.2</td>
<td>C</td>
<td>Rates of depression did not differ across all three groups. Patient's self-assessment of the degree of their impairment was correlated with depression. <strong>Score = 9</strong></td>
</tr>
<tr>
<td>16. Anson et al. (2009)</td>
<td>Investigate the</td>
<td>XS</td>
<td>SS</td>
<td>33</td>
<td>PTA</td>
<td>OM (HADS)</td>
<td>M = 18, SD = 19</td>
<td>C</td>
<td>Coping characteristics of avoidance, substance use, self-blame, worry and</td>
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<tr>
<td>Author(s)</td>
<td>Study Title</td>
<td>Research Question</td>
<td>Sample Size</td>
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<td>OMM</td>
<td>SM</td>
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<td>Ponsford (2006)</td>
<td>Relationship between coping style and emotional adjustment after a TBI.</td>
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<td>Wood &amp; Rutterford (2006)</td>
<td>Determine if long term psychosocial outcome following a severe TBI can be good.</td>
<td>XS SS 80</td>
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<td>Vickery et al. (2005)</td>
<td>Explore the association of self-concept with Quality of Life after TBI.</td>
<td>XS SS 19</td>
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<td>Al-Adawi et al. (2004)</td>
<td>Determine rates of apathy following TBI and to determine if apathy and depression are distinct</td>
<td>XS SS 80</td>
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<td>Hibbard et al. (2004)</td>
<td>Describe the link between depression and psycho-</td>
<td>PC SS 188</td>
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wishful thinking were associated with higher levels of depression/anxiety and lower self-esteem. Lower pre-morbid intelligence and greater self-awareness were associated with maladaptive coping. **Score = 8**

With a mean time since injury of 17 years, 72% lived independently, 28.7% were in fulltime employment, 60% were cohabiting or married. No serious emotional problems were detected using the HADS. **Score = 7**

Depression levels were elevated in the TBI group compared with normative data. Lower self-concept was associated with lower Quality of Life, as were depressive symptoms. **Score = 9**

Prevalence of Depression and apathy in this TBI Omani population was comparative to that reported in other studies. **Score = 8**

Four subgroups of depression identified by SCID and supported by BDI, non-depressed (47%), resolved depression (29%), late-onset depression (10%), and chronic depression (14%). 57% of participants...
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample Description</th>
<th>Measures</th>
<th>Findings</th>
<th>Score</th>
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<tr>
<td>Holsinger et al. (2002)</td>
<td>To investigate lifetime prevalence of depression in WWII veterans, following TBI in 1944-45</td>
<td>Sample of WWII veterans (n=1198) with TBI in 1944-45</td>
<td>- PTA &amp; LOC</td>
<td>Lifetime prevalence of depression was greater in head injured group than in the control group, and this extended to levels of current depression. The lifetime risk for depression was greater for those with more severe brain injuries.</td>
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<td>Glenn et al. (2000)</td>
<td>Investigate the prevalence of depression amongst outpatient TBI survivors.</td>
<td>Sample of outpatient TBI survivors (n=41)</td>
<td>- GCS &amp; LOC</td>
<td>59% sample scored within the depressed categories of the BDI-II and 34% scored within the moderate to severe categories. Depression and age, female gender, mild TBI, use of antidepressant drugs demonstrated a positive relationship using logistic regression.</td>
<td>11</td>
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<tr>
<td>Kreutzer et al. (2000)</td>
<td>Investigate usefulness of NFI to measure DSM-IV criteria for depression</td>
<td>Sample of TBI survivors (n=70)</td>
<td>- LOC</td>
<td>75% participants reported symptoms of psychomotor agitation/retardation. Other commonly reported symptoms were: Fatigue (46%), Frustration (41%), and poor concentration (38%).</td>
<td>8</td>
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<tr>
<td>Finset &amp; Andersson (2000)</td>
<td>Investigate coping strategies in people with ABI</td>
<td>Sample of students with ABI (n=71)</td>
<td>- All Brain lesions identifiable by CT, MRI or EEG.</td>
<td>Avoidance and approach coping styles were elicited. Avoidant coping but not lesion location associated with depression. Avoidant coping, apathy and left hemisphere lesions contributed to variance for depression.</td>
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<tr>
<td>Study ID</td>
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<td>28. Curran et al. (2000)</td>
<td>Measure levels of depression in severe TBI patients up to 5 years post-injury</td>
<td>XS SS 88TBI, Orthopedic (n=128) PTA 100% &gt;Severe OM (BDI) TBI 57% Comparison 56%</td>
<td>12-60 C</td>
<td>There were no significant differences between orthopaedic and TBI groups on anxiety or depression. A majority of both groups reported significant levels of emotional distress.</td>
<td>11</td>
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<tr>
<td>29. Wallace &amp; Bogner (2000)</td>
<td>Investigate difference in reporting of deficits from TBI patient to significant other.</td>
<td>XS SS 50 None Only moderate-severe included. OM (BDI)</td>
<td>M=24 SD=24 C</td>
<td>40% and 54% of people with brain injury report symptoms of depression and anxiety respectively. No significant correlation found between emotional distress of significant other and patient.</td>
<td>7</td>
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<tr>
<td>31. Satz et al. (1998a)</td>
<td>Determine the extent of depression symptoms following TBI</td>
<td>XS MS 100 CS Bodily Injury (n=30) GCS NR OM (SCL-90) TBI 24% Comparison 3.3%</td>
<td>6 C</td>
<td>The majority of people in poorer outcome categories on Glasgow Outcome Scale, were classified as depressed. No association was detected between depression status and neuropsychological performance.</td>
<td>11</td>
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<td>32. Jorge et al. (1993)</td>
<td>Determine the symptoms associated with depression after TBI.</td>
<td>PC SS 58 CS None NR OM (HDRS) Initial(29%), 3months(31%), 6months(28%), 1year(26%)</td>
<td>0-12 C</td>
<td>Frequency of vegetative and psychological symptoms of depression was 3 times greater in the depressed than non-depressed group.</td>
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<td>33. Alway et al. (2012)</td>
<td>Investigate the association between family expressed emotion &amp;</td>
<td>XS SS 43 PTA 23.9% Moderate 69% Severe OM (HADS) 9.3% Mild symptoms</td>
<td>M=30 SD=1.5 D</td>
<td>Criticism and emotional over-involvement associated with levels of anxiety and depression in the individual with a TBI.</td>
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<td>emotional distress.</td>
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<td>34. Senathi-Raja (2010)</td>
<td>Investigate the effect of age and time since injury on emotional distress in patients with a TBI.</td>
<td>XS</td>
<td>SS</td>
<td>112</td>
<td>GCS &amp; PTA, Age matched control (n=112)</td>
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|   | Examine the frequency of psychiatric disorders 1 year after TBI | PC | SS | 122 | GCS & PTA | SM (SCID) | 19% at 3-6m 31% at 6-12m | 3-12 | C | More than 50% of the sample had a pre-existing psychiatric disorder at the time of TBI. Pre-injury psychiatric illness was significantly associated with psychiatric illness after TBI. 60.8% of the sample had a post-injury psychiatric disorder in the year following TBI. |
|   |  | 2 | 2 | 2 | 1 | 1 | 1 | 1 | | Score = 9 |

Description of terms: BDI, Beck Depression Inventory; BDI-II, Beck Depression Inventory-II; CIDI, Composite International Diagnostic Interview; DASS, Depression Anxiety Stress Scale; HADS, Hospital Anxiety and Depression Scale; HDRS, Hamilton Depression Rating Scale; MADRAS, Montgomery and Asberg Depression Rating Scale; MDISD, Modified Diagnostic Interview Schedule for Depression; NFI, Neurobehavioural Functioning Inventory; PHQ-9, Patient Health Questionnaire-9; SCID, Structured Clinical Interview for DSM-IV; SCL-90, Symptom Checklist-90; ZDS, Zung Depression Scale.
Description of Studies

The range of scores for the studies reviewed was 7 to 11 out of a maximum 13; the median score of the studies was 9. Of the 26 studies reviewed, only those studies in the upper-tertile of potential scores (≥9) were deemed to be of adequate quality (Barley et al. 2011; Feder et al. 2006). Fifteen studies met this criterion and are discussed in detail below.

Summary of Methodology

With regards to the methodology of the reviewed studies, ten studies used cohort designs, of which four utilised prospective cohort designs and six employed retrospective cohort designs. Five studies were of cross sectional design and none of the studies reviewed used case-control designs.

Eight (53.3%) studies reported on their sampling methods. Of those studies that did report their sampling method four (26.7%) used consecutive sampling, two used random sampling (13.3%) and two studies (13.3%) collected data from an existing database. The existing databases, from which data was collected, were the Traumatic Brain Injury Model Systems (TBIMS) national database (Hart et al. 2012) and WW2 military medical records databases (Holsinger et al. 2002) both of which recruited from multiple sites. Two thirds of the reviewed studies (n=10) recruited from single sites and the remainder (n=5) recruited from multiple sites.

The sample sizes of the reviewed studies varied considerably. The smallest sample size reported was 19 (Vickery et al. 2005) and the largest was 1089 (Hart et al. 2012), from the existing TBIMS database.

The majority of the reviewed studies (n= 11, 73.3%) did not use control or comparison groups; therefore, their results relied only upon data collected from those with traumatic brain injuries. Three studies utilised comparison groups, comprised of orthopaedic (Curran et al. 2000), bodily injury (Satz et al. 1998) and non-head injury (Holsinger et al. 2002) participants. There was a single study that included an age-matched control group (Senathi-Raja, 2010).
Demographics

All studies reported basic demographic information, such as age and gender ratio; however, reporting of more specific demographic information (e.g. ethnicity) was less consistent across the reviewed studies. In most studies the mean age of participants ranged from 29.7 to 48.1 years old with one study having a mean age of 73.2 (Holsinger et al. 2002). Participants were predominantly male, with 80% of studies recruiting between 60% and 80% male participants. Most studies were conducted in the United States of America (n=7, 46.7%) or Australia (n=6, 40%) with one study being conducted in the United Kingdom (Ownsworth et al. 2011) and one more conducted in Norway (Andelic et al. 2009).

In the reviewed studies, reporting of ethnicity information was less common (n=5, 33.3%) with the predominant ethnicity of participants being white (63-100% of the sample). Education level was reported more frequently (n=8, 53.3%), reflecting the importance of this information in the TBI population. Mean length of education was relatively consistent with studies reporting between 11.7 and 12.9 years of education. Cause of injury was reported by nine (60%) studies; road traffic accidents (RTA) were the main cause of TBI in all studies that reported it.

Time since injury was reliably reported by all studies; furthermore, time since injury varied greatly among the studies. One study was conducted exclusively with inpatients (Malec et al. 2010); five (33.3%) studies conducted their research in the first year after discharge from hospital. The majority of studies (n=8, 53.3%) were conducted between 1 and 10 years post injury. A single study (Holsinger et al. 2002) investigated lifetime prevalence of depression following TBI and was conducted 50 years post-injury.

Traumatic Brain Injury

The vast majority ascertained TBI severity from medical records and so the validity of those assessments could not be determined as they were beyond the scope of the studies reviewed. All but one study (Hart et al. 2012) were explicit in reporting how severity of TBI was determined. Three studies (Gould et al. 2011; Holsinger et al. 2002; Satz et al. 1998) did not report the frequency of participants by severity of TBI. Three main methods were used to determine severity of traumatic brain injury in the reviewed studies: Glasgow Coma Scale (GCS), length of post-traumatic amnesia (PTA) and length of loss of consciousness (LOC).
Nine (60%) studies used the Glasgow Coma Scale (GCS) to determine the severity of the brain injury of participants. Participants’ scores were categorised consistently across all nine studies that used GCS to do so. GCS scores greater than or equal to 13 (out of a maximum of 15) were categorised as mild severity; scores between 9 and 12 were rated as moderate severity; while scores less than 8 were categorised as severe TBI.

Eight (53.3%) studies used length of Post-Traumatic Amnesia (PTA) as an indicator of the severity of the TBI sustained. There was a lack of consistency in how TBI severity was categorised based on length of PTA. Three studies categorised severity using length of PTA as follows: <24hours as mild severity, 1 to 7 days as moderate severity and >1 week as severe TBI. However, four studies combined mild and moderate severity for those with a length of PTA less than one day, with any longer time in PTA classified as severe TBI.

Two (13.3%) studies reported loss of consciousness (LOC) following TBI; however, neither study explicitly categorised severity of TBI based on LOC.

Five studies (66.6%) used a combination of any two of these three methods with the most common being PTA and GCS (n=4).

**Depression**

The studies reviewed used a wide range of both objective and subjective measures of depression. Twelve studies used seven different objective measures to measure depression. The most commonly utilised tests were the Beck Depression Inventory (BDI: n=3, 25%) which reported prevalence rates of 31% (Andelic et al. 2009), 35% (Hibbard et al. 2004) and 57% (Curran et al. 2000). Its updated version, the BDI-II, (n=3, 25%), consistently reported lower prevalence rates of 1% (Hudak et al. 2012), 10% moderate depression (Malec et al. 2010), and 12% severe depression (Mickery et al. 2005). The next most commonly used tool to measure depression was the Hospital Anxiety and Depression Scale (n=2, 16.7%) with reported prevalence rates of 37% (Senathis-Raja, 2010) and 46% (Draper et al. 2007).

More consistent results were found in the four remaining studies (n=4, 33.3%) that each study used a different measure of depression. Hart et al. 2012 used the Patient Health Questionnaire (PHQ-9) and reported a prevalence rate of 26%. A similar prevalence rate (27%) was reported by Ownsworth et al. (2011) who used the
Depression Anxiety Stress Scale (DASS). Weddell (2010) reported a prevalence rate of 25.6% using the Zung Depression Scale (ZDS) and Satz et al. (1998a) used the Symptom Checklist-90 (SCL-90) and reported a prevalence rate of 24%. None of the studies reviewed reported using more than one objective measure of depression.

Four studies used clinical diagnosis to measure the prevalence of depression symptoms. Three of these studies (75%) used the Structured Clinical Interview for DSM-IV (SCID) with reported prevalence rates of 31% (Gould et al. 2011), 35% (Hibbard et al. 2004) and 46% (Whelan-Goodinson et al. 2012). The other study used the Modified Diagnostic Interview Schedule for Depression (MDISD) and reported current prevalence rates of depression of 11.2% 47 years following injury (Holsinger et al. 2002). Only one study, Hibbard et al. (2004), used both clinical diagnosis (SCID) and an objective measure (BDI) of depression.

All studies reported the percentage of their sample considered to have a diagnosis of depression or clinically significant depressive symptoms. The prevalence of depression in those with a moderate to severe head injury ranged from 1% to 57%. The majority (n= 12, 80%) of studies reported prevalence rates of depression between 19% and 46%. Lifetime prevalence of depression, reported by Holsinger et al. (2002), was 18.5%. Prevalence of depression in the non-head injury control or comparison groups ranged from 3.3% to 56%.

Discussion

This review aimed to summarise the quality of existing research into the prevalence of depression following TBI, over the past 17 years. The studies reviewed scored highly in the quality assessment tool devised for this review; although, 15 studies clearly contributed to the understanding of the prevalence of depression following TBI. The studies in this review consistently reported higher prevalence rates of depression in people following TBI, both in the short and long term, than the general population, with a systematic review reporting pooled 1-year prevalence of depression at 4.1% (Waraich et al. 2004).

Whilst this review is the first systematic review on the prevalence of depression following TBI, two (non-systematic) literature reviews (Busch & Alpern, 1998; Morton
& Wehman, 1995) have been conducted previously. The results of the current review are consistent with Busch and Alpern’s (1998) review, who found depressive symptoms in at least 35% of people following mild TBI. Busch and Alpern also reported on a number of factors influencing the rates of depression reported, including time since injury, measure/method used to measure depression, unknown severity of injury in addition to a lack of control or comparison groups. Morton and Wehman (1995) reported on the reduction in social support, available activities and psychological functioning, including anxiety and depression. Studies reported on in this review also comment on the wider impact of TBI on the individual, including reduced levels of employment (Andelic et al. 2009; Wood & Rutterfood, 2006) and quality of life (Andelic et al. 2009; Vickery et al. 2005).

The variance in reported depression rates ranged from 1% (Hudak et al. 2012) to 57% (Curran et al. 2000). The majority of studies (13/15) reported prevalence rates between 10% and 46%. Those studies that used a comparison or control group largely reported an elevated prevalence of depression in the brain injury group (Holsinger et al. 2002; Satz et al. 1998a; Senathis-Raja, 2010) compared with the comparison or control group. The study by Curran et al. (2000) was the exception to this finding, and they reported equitable rates of depression between the head injury (57%) and orthopaedic injury (56%) groups. Overall there is a consistent indication that people are at least twice more likely to develop depression following a brain injury than those who have not.

The factors contributing to the variance in depression rates are likely to be complex and many. Severity of injury did not appear to be associated with prevalence of depression (Hudak et al. 2012; Malec et al. 2010). A degree of variance in the prevalence rates reported can be attributed to the depression measure used. Studies using the HADS and BDI reported prevalence rates between 37-46% (Draper et al. 2007; Senathis-Raja, 2010) and 31-57% (Andelic et al. 2009; Curran et al. 2000; Hibbard et al. 2004) respectively; whereas, studies using the BDI-II reported lower prevalence rates between 1% and 12% (Hudak et al. 2012; Malec et al. 2010; Mickery et al. 2005).

It was evident that prevalence rates between studies using the same measure were more consistent. This suggests a good degree of reliability for the measures used; furthermore, this held true for diagnostic measures of depression such as the SCID which reported prevalence rates between 31% and 46% (Gould et al. 2011; Hibbard et al. 2004; Whelan-Goodinson et al. 2012). The comparable rates of depression between
diagnostic and self-report methods challenges the assumption of the current review that self-report measures were categorised as subjective and diagnostic measures categorised as objective. The results of the current review suggest this distinction may be inaccurate. Indeed Hibbard et al. (2004) argue that self-report measures of depression reflect the person’s perceptions of their psychosocial functioning as opposed to the reality of their psychosocial functioning. The current review demonstrates that, despite differences in methodology, diagnostic and self-report methods of measuring depression report comparable prevalence rates of depression.

Time since injury may also be a factor influencing prevalence rates of depression after TBI. Two of the reviewed studies compared rates of depression at more than one time-point and reported slight increases in the prevalence rates. Ownsworth et al. (2011) reported an increase from 24% at discharge to 27% at 3 months; Gould et al. (2011) reported rates of depression increasing from 19% at 3-6 months to 31% at 6-12 months. This contradicts the findings of Hibbard et al. (2004) who reported that time since injury did not impact on prevalence rates of depression. The interaction of time since injury on the development of depression is undoubtedly complex, as are other factors influencing recovery from a brain injury, and requires further research.

**Review Limitations**

A number of limitations of this review came from the limits imposed upon the literature search. This made the search more focused but inevitably excluded several papers that contribute to the literature on TBI and Depression. One of the most apparent limitations of this review was that the literature searched was limited to the years between 1995 and 2012. The reason for this was that a review article conducted by Morton & Wehman (1995) had reviewed the literature prior to this. A number of studies that only investigated depression following mild traumatic brain injury were also excluded from this review because this literature had been reviewed (Busch & Alpern, 1998).

The use of different measures of depression impacted on the variance in the rates of depression reported. The use of both diagnostic, e.g. SCID, and psychometric, e.g. BDI-II, measures of depression reflects the dissonance between the psychiatric/medical and psychological models of depression. The impact of differing measures on the variance in depression rates was exacerbated by the large range of
length of follow-up employed by the studies reviewed. The challenge of this review was to accommodate the wide range of assessment tools measuring depression.

The large majority of studies were conducted in either the USA or Australia. This is unsurprising given that studies were restricted to those written in English; however, it harms the generalisability of the findings of this review to other cultures around the world. There is plentiful research into the prevalence of depression in non-English speaking countries, including Norway (Andelic et al. 2009), Oman (Al-Adawi et al. 2004), and Japan (Matsuoka et al. 2008). The need to consider ethnicity is more pronounced when studies have concluded that reporting of depression after TBI varies depending on ethnicity (Arango-Lasprilla et al. 2012). The limited range of countries of the reviewed studies means that caution should be applied when using the prevalence data reported in this review to describe depression after TBI in non-western countries.

Research implications

This review highlights areas of need for future research. More research is needed to development of a purpose-built tool to measure depression in a TBI population, given the overlap between depression and TBI symptoms. Such a measure would need to take into account the effect of TBI on factors commonly measured in depression scales such as fatigue, and psychomotor slowness. Many of the measures used to measure depression in the studies included in this review were not designed for or adapted for use with a TBI sample. Self-report measures can be a valid tool in TBI populations despite impaired self-awareness being a common result of TBI. Although some self-report measures were previously validated in a TBI sample, e.g. PHQ-9 (Fann et al. 2005) and BDI (Green et al. 2001), this was not the case for all measures of depression. A self-report measure designed specifically for use in the TBI population would better enable researchers and clinicians alike to measure depression in people with TBI.

Prior research has established that self-report measures of depression are a reliable method of measuring depression in a TBI population (Kinsella et al. 1988). In developing a measure of depression it would be beneficial to measure a number of factors that research has shown correlate highly with a diagnosis of depression following TBI: avoidant coping style (Anson & Ponsford, 2006; Finset & Andersson, 2000), self-blame (Anson & Ponsford, 2006), lower self-perception of functioning (Hudak et al. 2012; Malec et al. 2010) apathy (Finset & Andersson, 2000).
Some factors clearly overlap between depression and those directly resulting from the brain injury (Kreutzer, 2001), such as fatigue and poor concentration. It would be beneficial to consider excluding or limiting the impact of physical factors when developing a new measure of depression. For example psychomotor agitation may not discriminate between those depressed and those not depressed following TBI as Kreutzer et al. (2000) reported that 75% of patients reported symptoms of psychomotor agitation/retardation following TBI.

In conclusion a measure of depression for use in a TBI population should focus more on the psychological, emotional and social aspects of depression and exclude or limit physical aspects of depression. The measure should be accessible to those with a head injury, e.g. short to avoid fatigue; finally, it should be developed and have normative data for patients with a brain injury.

There is a distinct paucity of research into non-traumatic or acquired brain injury. The lack of research into depression following a range of acquired brain injuries, e.g. brain tumour, neuropathy, neurodegenerative disease, prevents the generalisability of research in this area, and thus of this review, to the general neurological population. The exclusion of non-traumatic brain injury is understandable given the heterogeneity of this population in comparison to traumatic brain injury samples. More research is required to identify the prevalence of psychological distress, including depression and anxiety in the acquired brain injury (ABI) population.

The need to investigate depression in ABI has already been discussed but there is a scarcity of research investigating the prevalence of depression in other areas of the brain injury population. Given that the two most at-risk groups for head injury are those between the ages of 15 and 24 (Kay & Teasdale, 2001), and the elderly (Rothweiler, Temkin & Dikmen, 1998), there is a need for research to investigate these subsets of the general population. A recent systematic review by Menzel (2008) into TBI and depression in the elderly, found that only one study (Levin, Goldstein & MacKenzie, 1997) reported the prevalence of depression (31%) in people over the age of 65. Research into the prevalence of depression, or emotional consequence in general, following TBI in children and adolescents is similarly scarce (Kirkwood et al. 2000).

It remains unclear whether depression is a cause or consequence of functional disability in people after a TBI or if there are other factor involved in the relationship. While current research is inconclusive (Hudak et al. 2012; Schonberger et al. 2011) into the relationship between functional disability and depression after TBI is important
to inform treatment and rehabilitation programmes. The authors recommend that following the development of an appropriate measure of depression in people with a TBI, that research focus on investigating this relationship further.

Clinical implications

Clearly, depression following TBI is not inevitable. Consideration should be given towards protective factors that may increase resilience to depression following TBI, such as access to a comprehensive rehabilitation programme (Draper, Ponsford & Schonberger, 2007), coping style (Anson & Ponsford, 2006) and high levels of social support (Seel et al. 2003). Equally an understanding of the individual factors increasing emotional distress and depression following a TBI, such as increasing self-awareness (Martin et al. 2003), pre-injury psychiatric illness (Whelan-Goodinson et al. 2010) and high levels of dependency (Schonberger et al. 2011), would be essential in identifying those people most at risk of developing depression.

There is a need to communicate clear research findings to the public. Kreutzer, Seel and Gourley (2001) argued that the head injury community does not receive a coherent or complete picture of depression after TBI from researchers. Increasing the awareness that depression after TBI is a relatively frequent occurrence to healthcare professionals, e.g. G.Ps, hospital and rehabilitation staff, would enable a quicker and more appropriate response to the psychological distress of the individual who has suffered a TBI.

More clearly explaining the effects of TBI on the individual would be a preventative act. To be more cost effective this information could be targeted towards the most at-risk groups of the population. Delivery of psycho-education and prevention programmes to schools and colleges to people aged between 15 and 24 (Kay & Teasdale, 2001), and also to community/day centres to those people over 65 (Rothweiler, Temkin & Dikmen, 1998). To ensure the efficacy of such preventative programmes, appropriate research in this area should be considered.

There is extensive focus on physical rehabilitation and recovery following TBI; however, this review highlights the need for more focus on the psychological recovery of people following TBI. The emotional consequences of TBI must first be acknowledged and screened for post-TBI before appropriate support/intervention is implemented in those cases where emotional recovery has been identified as being problematic. Staff must have sufficient training and support in detecting depression in
people following TBI; furthermore, appropriate pathways need to be devised to offer suitable treatment to those people with depression following TBI.

**Conclusion**

This review aimed to systematically review the literature into depression following traumatic brain injury, in the general adult population. Depression following TBI can be a long-lasting debilitating consequence and approximately 19-46% of people will develop depression following a TBI. Research shortages are clear in the areas of elderly and children who suffered a TBI. The heterogeneity of tools measuring depression in the reviewed studies could account for the range of prevalence rates reported, highlighting the need to develop a measure of depression for use specifically with the TBI population. By increasing the awareness and training of healthcare staff in detecting and treating depression following TBI, the clinical implications of this review may be realised.
References


Dementia Care Mapping in Clinical Neuroscience Settings: Cognitive Impairment and Dependency

A.J. Leigh\textsuperscript{1}, K. O’Hanlon\textsuperscript{1}, R. Sheldrick\textsuperscript{1+2}, C. Surr\textsuperscript{3}, & D.J. Hare\textsuperscript{1}

2013

1 Department of Clinical Psychology, University of Manchester, Manchester, UK
2 Department of Neuropsychology, Salford Royal, Salford, UK
3 Bradford Dementia Group, Bradford University, UK
Abstract

**Background:** Person-centred care can improve the well-being of patients and is therefore a key driver in healthcare developments in the UK. The current study aims to investigate the complex relationship between cognitive impairment, dependency and well-being in people with a wide range of acquired brain and spinal injuries.

**Method:** Sixty Five participants, with varied acquired brain and spinal injuries, were selected by convenience sampling from six inpatient clinical neuroscience settings. Participants were observed using Care Mapping – Neurorehabilitation (DCM-NR) and categorised based on severity of cognitive impairment.

**Results:** A significant difference in the behaviours participants engaged in, their well-being and dependency was found between the severe cognitive impairment group and the mild, moderate or no cognitive impairment groups. Dependency and cognitive impairment accounted for 23.9% of the variance in well-being scores and 17.2% of the variance in potential for positive engagement.

**Conclusions:** The current study highlights the impact of severe cognitive impairment and dependency on the behaviours patients engaged in and their well-being. It also affirms the utility of DCM-NR in measuring person centred care. Consideration is given to developing DCM-NR as a process that may improve person centred care in neuroscience settings.

**Keywords:** Cognitive Impairment, DCM, Dementia Care Mapping, Dependency, Neurorehabilitation.
Introduction

Person-centred care

Person-centred care (PCC) has various definitions and indeed a range of synonymous terms such as individualised care and patient-centred care. The common theme across the definitions of PCC is that the focus of healthcare should be on the person and not on their illness (Edvardsson & Innes, 2010).

PCC has been a key driver in improving healthcare provision in the United Kingdom (Department of Health, 2010; The Scottish Government, 2010). While initially applied to the area of dementia care following the influence of Kitwood’s work on personhood (1997), PCC is recognised as being instrumental in providing the best care for those with a range of neurological conditions such as stroke (National Institute for Health and Care Excellence: NICE, 2008), head injury (NICE, 2007) as well as dementia (NICE, 2006).

Dementia Care Mapping

Kitwood’s work on PCC (1997) led to the development of Dementia Care Mapping (DCM), currently in its 8th edition (Bradford Dementia Group, 2005). DCM is a structured observational tool to measure the level of PCC people with dementia are receiving from within formal health and social care settings. It involves observing (called “mapping”) one or more individuals in a communal area and periodically recording their behaviour into one of 23 behaviour category codes (BCC), determining their level of mood and engagement (ME values) in that activity, as well as any significant interactions with staff. The mean of the ME values over the time period mapped is used as an indicator of that person’s state of well-being (Well-Ill Being: WIB score) for that time period. In addition, the percentage of time spent engaging in behaviours that have potential for the individual to reach high levels of well-being can be calculated as Potential for Positive Engagement (PPE). Research has demonstrated that DCM has good internal consistency, test-retest and inter-rater reliabilities as well as correlating with other measures of quality of life (Fossey, Lee & Ballard, 2002; Brooker, 2005).

DCM is also a process to promote and improve the level of PCC in formal health and social care settings for people with dementia. This is done by feeding back the
observations and recordings to staff teams and subsequently developing action plans, which are implemented, monitored and further actions developed through subsequent cycles of mapping. DCM relies on the premise that by improving PCC, the well-being and quality of life of the person with dementia will improve.

A number of published studies report the beneficial affect DCM has on the well-being of patients (Brooker, 2005; Brooker et al. 1998; Martin & Younger, 2001). DCM has also been shown to impact on other indicators of well-being, such as reduced verbal and physical agitation and anxiety (Chenoweth & Jeon, 2007; Kuiper et al. 2009), reduction in numbers of falls (Chenoweth et al. 2009) and decreased levels of depression (Chenoweth & Jeon, 2007). Many studies have also shown that DCM can support staff in understanding the perspective of the person with dementia, leading to staff having increased confidence in implementing person-centred care (Beavis, Simpson & Graham, 2002; Mansah, Coulon & Brown, 2008). Studies have also shown that DCM can result in care staff feeling more connected with patients (Kuiper et al. 2009) and improved quality of staff-patient interactions (Chenoweth & Jeon, 2007).

While DCM was originally devised for use in dementia care settings, research has successfully applied the DCM tool and methodology to a range of other healthcare settings and with different patient groups. DCM has been implemented in learning disability residential services (Persaud & Jaycock, 2001) and hospital wards for the physically ill (Woolley et al. 2008). Despite DCM not being designed for use in these settings or with these patient groups, researchers have found it to be both useful and effective in measuring PCC, well-being and as an observational tool in illustrating the activities in those care settings. Both studies suggested modifications to DCM so that it could be adapted for use in their respective healthcare settings.

The similarities between people with dementia and people with acquired brain injury, such as cognitive, emotional and behavioural difficulties, are readily apparent. Therefore, recent research has investigated adapting DCM for use in neurorehabilitation settings (McIntosh et al. 2012; Westbrook et al. 2013). Utilising Q-methodology alongside DCM in a neurorehabilitation ward it was concluded that DCM was feasible and acceptable by both staff and patients. Following these initial studies and the researchers’ recommendations for amendments to DCM, a manual for using DCM in neurorehabilitation settings was developed: Care Mapping – Neurorehabilitation (DCM-NR: Bradford Dementia Group, 2012).
Clinical neuroscience settings

Patients in clinical neuroscience settings vary in aetiology, including traumatic brain injury, stroke, epilepsy and spinal cord injury. The incidence of traumatic brain injury (TBI) is 235 per 100,000 (Tagliaferri et al. 2006), stroke is 104 per 100,000 (Lee, Shafe & Cowie, 2011), with spinal cord injuries less common with an estimated incidence of 1 - 8.3 per 100,000 (Wyndaele & Wyndaele, 2006). Those who have suffered an acquired brain injury (ABI) can face a range of physical, behavioural, and socio-economic disabilities (Finset & Andersson, 2000) that have a negative impact on the individual’s quality of life (Vickery, Gontkovsky & Caroselli, 2005; Andelic et al. 2009) and often require long-term care and rehabilitation.

The cognitive and emotional sequelae after ABI are considered to be the hardest to adjust to and have the greatest impact on well-being (Franulic et al. 2004). Some DCM research has looked at the effect of cognitive impairment on PCC and well-being, albeit in people with dementia. Much of this evidence is equivocal with Edelman, Kuhn & Fulton (2004) finding those with greater cognitive impairment displaying lower well-being, while other researchers report no significant relationship between cognitive impairment and well-being or activity as measured by DCM (Gigliotti, Jarrott & Yorgason, 2004; Jarrot & Bruno, 2003). Research in this area relies on measuring cognitive impairment accurately, with most studies using the Mini-mental state examination (MMSE: Folstein et al. 1975) as the primary, or only measure of cognitive impairment.

In addition to cognitive impairment, other factors influence well-being following ABI, principal of which is functional ability. ABI frequently has a negative impact on functional ability (Vickery, Gontkovsky & Caroselli, 2005) with researchers and governments alike recognising that TBI is a predominant cause of disability, particularly in those under the age of 35 years (Seel et al. 2003). With unemployment following TBI ranging from 10% to 70% (McCrimmon & Oddy, 2006) and those who do return to work often do so in a different role than prior to their injury. Functional ability, therefore, has a very large impact on well-being (Vickery, Gontkovsky & Caroselli, 2005), with those who have less functional ability being more likely to develop a psychological condition, such as depression or anxiety (Schonberger et al. 2011).

Measuring functional ability in acute hospital settings is highly important for determining staffing levels and providing good quality care to patients. Thus functional ability in acute hospital settings is seen as level of dependency, i.e. the level of support
needed by staff or others to function. A widely used and validated measure of dependency is the Northwick Park Dependency Scale (Siegert & Turner-Stokes, 2010; Turner-Stokes et al. 1998).

DCM research has started to investigate the complexity of functional ability or its inverse, dependency, and its relation to well-being. Higher dependency has been linked to lower well-being scores (Edelman, Kuhn & Fulton, 2004; Thornton, Hatton & Tatham, 2004). Brooker (1998) linked this relationship to a mediating factor of poorer care for those with higher dependency, finding that with 3 cycles of DCM the relationship of lower well-being for those more dependent patients was no longer significant. Brooker (2005) recommended the routine use of a measure of dependency alongside DCM to investigate this relationship further.

NHS Trusts are currently being challenged to implement safer, better quality care in response to the findings of the Francis report (Francis, 2013) with person-centred care a likely approach many NHS Trusts may choose to adopt. Research suggests that DCM can help to deliver PCC for people with dementia in NHS settings and more recent studies indicate that DCM-NR may be a feasible and acceptable tool and process to use in clinical neuroscience settings. There remains a need to investigate whether there are similar patterns of effects of cognitive impairment and functional ability on well-being as measured through DCM-NR scores as seen in DCM studies. If this is the case then this indicates DCM-NR may not only be a useful process for helping staff to implement PCC, but may also provide valuable data about the impact of changes to care practice on patient well-being.

Aims and hypotheses

This study aimed to investigate the relationships between cognitive impairment, dependency and Well-being in a sample of patients from a range of clinical neuroscience settings. Three primary hypotheses were considered:

- H1) A negative relationship between dependency and the patient’s observed mood/engagement and potential for positive engagement (PPE).
  - H1a) Greater mood and engagement (DCM: WIB scores) will be observed in those patients with less dependency, as measured by the Northwick Park Dependency Scale.
• H1b) Higher PPE score (DCM) will be observed in those patients with less dependency (NPDS).

• H2) A negative relationship between cognitive impairment and the patient’s observed mood/engagement and PPE.
  o H2a) Greater mood and engagement (DCM: WIB scores) will be observed in those patients with less cognitive impairment.
  o H2b) Higher PPE score (DCM) will be observed in those patients with less cognitive impairment.

• H3) A positive relationship will be seen between cognitive impairment and dependency. Those patients with greater cognitive impairment will also have greater levels of dependency, as measured by the NPDS.
Method

Participants

A convenience sample of patients was recruited from six clinical neuroscience wards at Salford Royal NHS Foundation Trust, United Kingdom. The wards recruited from included diverse specialties: neurorehabilitation, neurosurgery, neurology, and stroke rehabilitation. Patients on these wards had a range of neurological conditions, including traumatic brain injury, cerebrovascular injuries, central nervous system tumours, neuropathy, and spinal cord injuries. A description of the demographic details for the participants is contained in Table 1.

An assessment of capacity to take part in the study was conducted with all participants. Consent was obtained from those with capacity and assent was gained from the nominated individual of those deemed to be lacking capacity to make the decision. Capacity was assessed on an on-going basis by a clinician (RS) qualified to do so, given the potential for participants to deteriorate or recover, over the course of the study.

Exclusion criteria of the study as a whole were limited to ensure the sample remained representative of the typical patients on the wards and exclusion criteria were not applied to the DCM-NR part of the study. Exclusion criteria were applied prior to any participant completing the Addenbrooke’s Cognitive Examination – Revised (ACE-R), these being under the age of 18, non-English speaking, in a minimally conscious state or in Post-Traumatic Amnesia (PTA) preventing completion of the task and obvious lack of suspected cognitive impairment. A total of 67 participants were recruited into the study, and observed using DCM-NR. Cognitive assessment using the ACE-R was completed with 29, although severity of cognitive impairment was determined for the remainder.

Measures

Care Mapping-Neurorehabilitation (DCM-NR)

DCM-NR (Bradford Dementia Group, 2012) is an adapted version of Dementia Care Mapping 8th Edition (DCM 8: Bradford Dementia Group, 2005) for use with neurological populations in a hospital setting. The DCM-NR was developed and it's feasibility and
acceptability on a neurorehabilitation ward was initially established by McIntosh et al. (2012) and Westbrook et al. (2013). A further study (O’Hanlon, *In preparation*) has examined its feasibility of use on a broad range of clinical neuroscience wards.

Participants in a communal area, such as a ward bay, are observed for a set length of time (2 ½ hours in this study). At three-minute intervals two recordings are made. (1) a Behaviour Category Code (BCC) is chosen from a list of 24 categories to record the behaviour the participant was engaged in during those 3 minutes. (2) the degree to which the participant was engaged in their behaviour and their mood is also recorded on a six point scale from +5 to -5 (WIB value). Any staff-participant interactions that either enhanced or diminished the person’s sense of self or well-being are also recorded independent of the time frame.

Amendments in DCM-NR (Bradford Dementia Group, 2012) primarily centre around the adaptation to an acute setting. As such, a BCC code of “M” for Medical care was included, and of “p” and “t” codes for use alongside standard BCC codes to indicate that the ‘curtains were closed around the patient’s bed’ or ‘therapeutic activity’ was taking place respectively.

Further amendments were the use of 3 minute time-intervals and a 2 ½ hour observation period. Fossey et al. (2002) showed that mapping over a shorter lunchtime period correlated well with longer full-day mapping. Fulton et al. (2006) expanded upon this and found that shorter mapping periods were feasible. Therefore it was decided to employ a 2 and a half hour map (using 3 minute time-frames) including a lunchtime period. As described, this was supported by previous research (Fossey et al. 2002; Fulton et al. 2006) while also satisfying DCM-NR requirements of a minimum of 48 time-frames for WIB and PPE calculations. Furthermore this methodology was agreed upon in collaboration with researchers at the Bradford Dementia Group and deemed acceptable by staff and ward managers.

DCM-NR produces a wide range of data to assess participants’ quality of life and quality of care. This can include an average of the participant’s ME values (WIB score) that is an indicator of well-being, as well as data on the range and type of activities participants were engaged with over the mapping period and the quality and quantity of staff interactions they received.
Dependency

Dependency was measured using the Northwick Park Dependency Scale (NPDS: Appendix 2) (Turner-Stokes et al. 1998). This is a widely used, reliable and valid measure of dependency (Siegert & Turner-Stokes, 2010), that was already routinely completed in all the clinical neuroscience settings included in this study. This was completed by the member of staff most able to complete this measure, typically a registered nurse or ward manager. The NPDS measures the amount of help someone needs regarding: mobility, personal care, safety awareness, communication and behaviour. The NPDS provides a score out of 100, with a greater score indicating more care needs and therefore higher dependency.

Cognitive Impairment

When considering how best to measure depression in an inpatient acquired brain injury population, the benefits of an in-depth neuropsychological assessment were weighed against the impact on the participants completing an in-depth assessment. Consideration was also given to the potential difficulties from completing a battery of neuropsychological measures in an acute hospital setting. A more in-depth neuropsychological assessment would have provided more detailed neuropsychological information but a large proportion of potential participants may have been unable to complete assessment and thus would have been excluded from the research. A brief screening measure would enable an assessment and judgment on level of cognitive impairment to be made with a wider range of participants while also being less taxing on participants. As this study sought to include as much of the clinical neuroscience population as possible it was decided that a brief screening measure was sufficient for the purposes of testing the hypotheses of this research. Of the available measures the Addenbrooke’s Cognitive Examination – revised (ACE-R: Moshi et al. 2006) (Appendix 3) was chosen due to its prior validation in neuroscience settings (Gaber, 2008) and its ability to detect mild cognitive impairment (Crawford et al. 2012). The ACE-R included and expanded upon the MMSE (Folstein et al. 1975) to measure the following cognitive domains: Attention and Orientation, Memory, Verbal Fluency, Language and Visuospatial abilities.

Participants were classified into four categories of cognitive impairment: severe, moderate, mild and no cognitive impairment. Categorisation was completed using a
combination of clinical judgment by an experienced clinician and the ACE-R as a standardised measure of cognitive impairment.

Clinical judgment was used to initially determine those participants who were unable to complete the ACE-R, e.g. those participants in a minimally conscious state or in post-traumatic amnesia (PTA) as it was deemed inappropriate to administer the ACE-R to participants presenting in this way. Those participants who could not complete the ACE-R were categorised by a qualified and experienced clinician (RS) as having ‘severe cognitive impairment’.

Those participants who completed the ACE-R and scored between 75 and 88 were categorised as having ‘mild cognitive impairment’ (Crawford et al. 2012). Those scoring below the mild cognitive impairment cut-off of 75 were categorised into the ‘moderate cognitive impairment’ group.

The final category of ‘no cognitive impairment’ comprised those participants scoring above the recommended cut-off of 88 (Crawford et al. 2012; Gaber, 2008; Mioshi et al. 2006). In addition, those participants with a spinal injury who were deemed to have no cognitive impairment by an experienced clinician were also classified in the ‘no cognitive impairment group’.

Due to the dynamic nature of inpatient wards and the variable presentation of the participants, it was not possible to administer the ACE-R to all those who may have been able. Where uncertainty of level of cognitive impairment existed, an experienced and qualified clinician consulted the patient medical records to categorise the participants.

**Procedure**

**Prior to mapping & interviews**

Staff members were informed at least one week prior to mapping about the research project and what it would entail. Patients were approached, at least 24 hours before the start of mapping, using convenience sampling, and informed (Appendix 4) about the research project by an experienced clinician. Formal consent was sought from both staff members (Appendix 5) and patients (Appendix 6) at least 24 hours before mapping was due to be undertaken. At the same time, the clinician also assessed
capacity and sought assent (Appendix 7) in those cases where the patient was deemed to lack capacity.

**Mapping**

Mapping was conducted as per the DCM-NR manual (Bradford Dementia Group, 2012) by two researchers (AL & KO’H) who had previously established adequate (>80%) inter-rater reliability. Mapping was conducted in both a quiet time and busier meal time to observe a range of activities on the bay. Typically this involved mapping from: 8.30-11am, and 12.30-3pm. One researcher sat in the bay where participants were to be mapped, in a position so that they could see and hear all participants with minimal movement. Each ward was mapped between two and four times either on the same day or on two consecutive days.

**After mapping**

Following the completion of the maps, staff and patient participants were thanked for their participation. It was at this time that those participants who were able were approached and asked to complete the ACE-R. All ACE-Rs were administered by a single researcher. Following the completion of the ACE-R the participant was debriefed about the research project and offered the opportunity to ask questions.

Data were analysed as per DCM-NR guidelines (Bradford Dementia Group, 2012) and the results disseminated to the staff teams via feedback sessions. A sample feedback report (Appendix 8) and a sample feedback leaflet (Appendix 9) are included in the appendices.

**Data Analysis**

**Summary of Cognitive Impairment**

Twenty six people completed the ACE-R, and their scores ranged from 54/100 to 95/100, with a mean score of 79.96/100 (SD=12.67). A number of participants (n=9) were unable to complete items from the visuospatial subtest that required drawing, due to motor impairments. In these cases missing data were replaced with the mean score from that subscale.
The number of participants in each of the four categories of severity of cognitive impairment (None, Mild, Moderate & Severe) is shown in Table 1. It was not possible to categorise one participant into one of these four categories because of inconclusive medical records; therefore, they were excluded from analyses involving cognitive impairment.

Summary of DCM Data

Inter-rater reliability above the recommended 80% (Bradford Dementia Group, 2012) was achieved and maintained for both researchers during the course of mapping. Mood and Engagement (ME) values, an indicator of the level of mood and engagement of each participant, were recorded on a six point scale at -5, -3, -1, +1, +3, and +5, with positive values reflecting positive mood and engagement. ME values were recorded every 3 minutes, giving a maximum of 50 ME values for each participant. Participant WIB scores, an index of the participant’s relative well-being over the mapped time period, were calculated by averaging each participant’s ME values over the whole time-frame. WIB scores ranged from -0.50 to 2.16 with a mean of 1.15 (SD=0.65).

Potential for Positive Engagement (PPE) was calculated as the percentage of time spent in behaviours that have a high potential for well-being over the time-frame. Behaviours with a high potential for well-being include: leisure, personal care, eating and talking with others (See Appendix 10 for a complete list of behaviour category codes with a high potential for well-being). Mean PPE was 62.75% (SD=28.18%) with a range of 2% to 100%. A significant positive correlation between WIB scores and PPE was detected at the 0.01 significance level (two tailed) ($r_s=0.620$, n=66, $p<0.001$).

For a more thorough description of the DCM-NR data, its acceptability and psychometric properties see O’Hanlon et al. *In preparation.*

Tests for Normality

Kolmogorov-Smirnov tests of normality were completed for participant scores on the NPDS, and their WIB and PPE scores. WIB scores (0.099, $P=0.192$) and NPDS scores (0.105, $p=0.074$) were considered to be normally distributed (0.05 significance level). PPE, however, was not normally distributed at a 0.05 significance level (0.133, $p=0.006$).
Results

Demographics

Sixty seven participants either gave consent or advice on their best wishes, by a nominated person, resulted in them being included in the study. It was not possible to access two participants’ medical records, giving a final sample size of 65. See Table 1 for a description of participant demographics.

Table 2. Participant Demographics

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<th>Participant Demographics (n=65)</th>
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Hypothesis 1: Analysis of Dependency & DCM

To test Hypothesis 1a, a Pearson’s correlation was conducted between NPDS and WIB scores, with a significant negative correlation detected \((r=-0.447, n=64, p<0.001)\).

To test Hypothesis 1b, a Spearman’s Rho correlation was performed between PPE and NPDS scores; with a significant negative correlation being detected \((r_s=-0.376, N=64, p=0.002)\).
Hypothesis 2: Analysis of Cognitive Impairment & DCM

To test hypothesis 2a, a one-way independent samples ANOVA was conducted to compare the effect of cognitive impairment on well-ill being (WIB) scores. There was a significant effect of cognitive impairment on WIB scores at the $p<0.05$ level for the four categories ($F(3, 60) = 9.910, p<0.001$). Post hoc comparisons using Tukey’s Test were completed. A significant difference in mean WIB scores was found between the severe ($M=0.36, SD=0.59$) and all other categories of cognitive impairment at the 0.05 level. No significant difference in means was found between the mild ($M=1.39, SD=0.56$), moderate ($M=1.30, SD=0.45$) and no cognitive impairment ($M=1.35, SD=0.54$) categories. Figure 1. shows the mean WIB scores for each of the four levels of cognitive impairment.

![Boxplot showing WIB scores for categories of cognitive impairment.](image)

To test Hypothesis 2b, a one-way independent sample ANOVA was conducted to determine the effect of cognitive impairment on Potential for positive engagement (PPE). A significant effect of cognitive impairment on PPE at the $p<0.05$ level for the
four categories (F (3, 60) = 5.20, p=0.003) was found. Post hoc comparisons revealed a significant difference between the severe category (M=36.66, SD=23.46) and the mild (M=74.02, SD=15.42) and no cognitive impairment (M=70.54, SD=27.42) categories. No significant difference was detected between the moderate cognitive impairment category (M=60.87, SD=30.27) and any other category.

Hypothesis 3: Analysis of Cognitive Impairment & Dependency

To test hypothesis 3, a one-way independent samples ANOVA was conducted to determine the effect of cognitive impairment on dependency. There was a significant effect of cognitive impairment on NPDS scores at the p<0.05 level for the four categories (F (3, 59) = 7.533, p<0.001). Post Hoc analysis revealed a significant difference between the severe cognitive impairment category (M=49.09, SD=14.59) and the mild (M=25.40, SD=17.19) and no cognitive impairment (M=20.54, SD=17.78) categories. No other significant difference in dependency was detected between the cognitive impairment categories.

Multiple Regression Analyses

Cognitive impairment and NPDS scores, significantly predicted well-being (WIB) scores and potential for positive engagement (PPE). Therefore, to further investigate these predictive effects, and thus hypotheses 1 and 2, multiple regression analyses were conducted.

With regards to WIB scores, a standard multiple regression was calculated and using the enter method a significant model was determined (F (2, 60) = 10.75, p<0.001), which accounted for approximately 23.9% of the variance in WIB scores (adjusted R Square = 0.239) with significant predictor variables, at the 0.05 level, of Cognitive Impairment (β=-0.291, p=0.026) and Dependency (β=-0.303, p=0.021).

Multiple regression analysis was also used to test if cognitive impairment and dependency predicted PPE. The results of the regression indicated that the two predictor variables accounted for 17.2% of the variance in PPE scores (Adjusted R Square = 0.172, F (2,60) = 7.45, P<0.001). Cognitive impairment (β=-0.277, p=0.042) predicted PPE alone; however, dependency (β=-0.239, p=0.077) did not predict PPE alone.
Discussion

The results of the current study support all three hypotheses. Relationships were identified between dependency and well-being (WIB scores) and behaviours with the potential to lead to greater well-being (PPE scores). This supports the majority of previous research indicating that those patients with greater dependency were observed to have lower well-being using Dementia Care Mapping (Edelman, Kuhn & Fulton, 2004; Thornton, Hatton & Tatham, 2004).

Cognitive impairment was identified as being a predictor of well-being and of potential for positive engagement. The prior evidence into how cognitive impairment affects DCM observations was unclear (Brooker, 2005); however, the results of this study support those of Edelman, Kuhn & Fulton (2004). Those participants with severe cognitive impairment were consistently observed to be in significantly lower well-being states and engaging in fewer behaviours leading to well-being. This finding is unsurprising given the wider range of cognitive impairment in this study than is usually seen in dementia settings. Several patients in the severe cognitive impairment category were in post-traumatic amnesia or minimally-conscious states.

With regards to the relationship between cognitive impairment and dependency, the current study supports the consensus that greater cognitive impairment leads to greater dependency (Seel et al. 2003; Vickery, Gontkovsky & Caroselli, 2005). The interaction of these two factors in influencing well-being is less clear and the present data demonstrates that both dependency and cognitive impairment contribute equally to the variance in well-being scores and potential for positive engagement. This indicates that patients in clinical neuroscience settings are particularly at risk of being in lower states of well-being, thus highlighting the need for systemic intervention in these settings. DCM-NR may meet this need as repeated rounds of DCM in an organisation supportive of PCC, has been demonstrated as efficacious in improving well-being, particularly in those with higher levels of dependency and cognitive impairment (Brooker et al. 1998).

The adaptations made to DCM to produce DCM-NR for use in clinical neuroscience settings were found to be appropriate in the current study. No major difficulties with assigning behaviour category codes or well-being values were identified; furthermore, the addition of certain codes to reflect the inpatient setting, e.g. curtains
being closed around the hospital bed were useful. The use of three-minute timeframes and of a single mapper-per-bay did not detract from the ability to measure person centred care in this study.

**Strengths and limitations of the study**

The strengths of this study lie in the range of neuroscience settings used, allowing for generalisations to be more confidently made. DCM-NR had previously only been piloted in a single neurorehabilitation setting (McIntosh et al. 2012; Westbrook et al. 2013). The range of settings included acute neurology, neurosurgery, and neurorehabilitation, resulting in a heterogeneous sample. While a heterogeneous sample aided the generalisability of the findings from this study, the heterogeneity of participants also led to difficulties in measuring cognitive impairment. Both the range of neuroscience settings and the wide range of participants included in this study strengthen the findings of this research in terms of ecological validity. To enhance the findings of this study further, DCM-NR could be applied to more intermediate and community-based neuroscience settings.

The adaptations to the DCM-NR approach, namely shorter time-frames and shorter observation periods, demonstrate the continuing efficacy of DCM-NR in line with recommendations of previous research. It is considered that the adaptations may make the tool more acceptable to use due to the reduced demand on staff time.

Another strength of this study is that it builds upon the DCM research conducted in dementia care settings and demonstrates the importance of those same issues in clinical neuroscience settings. Brooker (2005) argued that dependency should be recorded alongside DCM due to the potential for dependency to affect DCM scores. In findings that dependency leads to lower DCM scores, this study supports the importance of measuring dependency alongside DCM-NR. Furthermore research by Edelman et al. (2004) demonstrated that cognitive impairment impacts on DCM scores, in dementia care settings, and this study found comparable results in the clinical neuroscience population.

There are several limitations of this study inherent within its design. Observation-expectancy effects on staff and patients have been indicated in previous DCM research (Westbrook et al. 2013). The presence of an observer may have led to a change in staff interactions with patients resulting in an overestimation of patients’ well-being.
However, the presence of an observer may also have deterred staff from entering the observed bay for reasons other than essential/required care tasks.

The choice of time to observe may also have led to biased results. Although the time periods mapped were considered representative by staff, and previous DCM research had established that mapping during lunchtime was representative of the whole day (Fulton, Edelman & Kuhn, 2006) for health and social care dementia settings. There was no objective indication that the time mapped in the current study was representative of the day as a whole, due to DCM-NR research being in its infancy. The findings of Fulton, Edelman & Kuhn (2006) may not apply to acute hospital settings and further research would need to establish periods of the day representative of the day as a whole; this would be inherently difficult due to varying ward time-tables, visiting hours, and staff shifts. For example, staff reported during feedback sessions that night-shifts may exhibit less person-centred care than day-shifts.

The Addenbrooke’s Cognitive Examination – Revised (ACE-R: Moshi et al. 2006) was chosen as a measure of cognitive impairment for its ability to reliably detect mild cognitive impairment (Crawford et al. 2012). The ACE-R was originally designed to detect the cognitive impairment present in fronto-temporal-dementia and while it has been shown to be valid in a brain injury setting (Gaber, 2008), its use in this study was problematic. Firstly, the range of cognitive impairment exceeded the scope of the ACE-R with some participants too severely cognitively impaired to attempt the measure. This resulted in the severe cognitive impairment group being comprised of a wide range of patients, for example people who could communicate to people in a minimally conscious state. The lack of a standardised measure feasible for use across the severity range of cognitive impairment meant that clinical judgement was necessary to categorise those people unable to complete the ACE-R. Secondly, over a third of participants were unable to complete items on the visuo-spatial subscale due to motor impairments (e.g. hemiparesis) independent of cognitive impairment. Lastly, it was necessary to administer the ACE-R by the bedside of participants which resulted in a number of distractions and interruptions. Although every effort was made to minimise distractions, e.g. by using a side room or closing curtains around their bed; distractions likely had a detrimental effect on participant performance on the ACE-R. Despite previous research indicating its validity (Gaber, 2008), the difficulty in using the ACE-R in the current study raises the case for the development of a standardised measure of the full range of cognitive impairment in clinical inpatient neuroscience settings.
Implications for future research

There are a number of implications for future research from the current study. The need for a brief measure of cognitive impairment, for use with a broad range of cognitive impairment in patients residing in an acute hospital setting has been discussed.

The current study identified that those patients with severe cognitive impairment were more likely to be in states of lower well-being. Cognitive impairment is a broad term and comprises many functions. In order to better tailor cognitive rehabilitation, more research needs to be done to determine which domains of cognitive impairment impact on well-being the most and how rehabilitation can target these same domains. A study employing DCM (Potkins, 2003) found that extent of language impairment was significantly correlated with social withdrawal, reduced engagement in activities and level of depression.

DCM is regarded as both a set of observational tools and as a process to improve PCC. Most of the amendments to produce DCM-NR and subsequent research using DCM-NR or DCM research in neurorehabilitation populations have looked primarily at the use of the tool and not the process. While both the tool and process were deemed to be acceptable and feasible to staff and patients in initial pilot studies (McIntosh et al. 2012; Westbrook et al. 2013) and the feasibility further established in a range of neurorehabilitation settings (O’Hanlon, in progress), more research is required to develop the utility of DCM-NR as a process of improving PCC. Evaluating the effectiveness of DCM-NR in improving PCC, such as through the use of an intervention design study would help empower arguments for DCM-NR to become embedded in clinical neuroscience settings with the aim of improving PCC.

Clinical Implications

Following the findings of the Francis Report (2013), there is a need for an observational measure of person-centred care and patient well-being in acute hospital settings. The current study adds to the evidence base indicating that DCM-NR is effective in this regard. The current study also showed that patients with high levels of dependency and/or severe cognitive impairment are less likely to engage in behaviours with the potential for well-being and more likely to be in a state of low well-being, thus
identifying risk factors for diminished well-being. Those patients with high levels of dependency or severe cognitive impairment warrant increased focus and attention and DCM-NR is a way of ensuring their person-centred care needs are addressed.

Clinical neuroscience settings are more likely than most general wards in acute hospitals to have patients with severe cognitive impairment suggesting that the use of DCM-NR is particularly pertinent in those settings. Similarly high dependency and intensive care wards care for patients who are likely to be highly dependent and would also benefit most from routine care mapping to improve patient well-being and person-centred care. Repeated rounds of DCM in an organisation supportive of PCC, has been demonstrated as efficacious in improving well-being, particularly in those with higher levels of dependency and cognitive impairment (Brooker et al. 1998).

**Conclusion**

This study demonstrates that those patients with greater cognitive impairment and higher levels of dependency were observed to have lower well-being and that they engaged in behaviours less likely to lead to well-being. This study supported the implementation of DCM-NR to measure well-being and person-centred care in clinical neuroscience settings. Further research should focus on using DCM-NR to improve person centred care in these settings with a particular focus on how the well-being of those patients with severe cognitive impairment or high dependency could be improved.
References


Critical Appraisal

A.J. Leigh

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1 Department of Clinical Psychology, University of Manchester, Manchester, UK
Introduction

The aim of this critical appraisal is to evaluate both the systematic review and the research paper in discussing the salient issues that arose during the completion of this thesis. In reflecting on the systematic review and research study processes a number of areas warranted further discussion that were not possible in the respective papers. Working as part of a two person research team, conducting research in acute clinical neuroscience settings and areas pertinent to Care Mapping Neurorehabilitation are also considered.

This research is particularly timely given the Mid Staffordshire National Health Service (NHS) Foundation Trust Inquiry (Francis, 2013). This inquiry understandably drew media attention and the Department of Health (2013) outlined the importance of putting patients at the centre of their own care, in one of its many points of response to the aforementioned inquiry. The well-being of patients in hospital is essential and if person-centred care is to be implemented to improve well-being then there is a need for research in this area.

Being a part of a two-person research team

The research project described in paper two was conducted in collaboration with another research project being conducted by Katie O’Hanlon, as part of her thesis for a Doctorate in Clinical Psychology. While working as part of a two person research team was necessary to collect the care mapping data required, it also brought its own benefits and challenges. One benefit was that the studies were treated as one research project for the purposes of NHS Ethics and NHS Trust Research and Development applications as well as data collection. This made approval for the research projects more efficient and enabled the researchers to collect more data thus strengthening the findings of the individual research projects. With two researchers it was possible to check inter-rater reliability for both DCM mapping, which was an essential part of conducting DCM-NR (Bradford Dementia Group, 2012), and the quality assessment of studies in the systematic review. This was useful in ensuring that bias had not interfered with the method of either the systematic review or research methodology.

It was a challenge to ensure that the individual research projects were distinct, given that the data collection was shared. The two projects were defined clearly from the beginning, and regular supervision ensured that there was no blurring of the boundaries with respect to producing two distinct research papers. This thesis
described the relationships between cognitive impairment, dependency and care mapping data; whereas, the other research project was focused on the feasibility of Care Mapping – Neurorehabilitation (DCM-NR: Bradford Dementia Group, 2012).

Research in a Clinical Neuroscience Setting

Six percent of the UK population is expected to develop a neurological condition over their lifetime (Macdonald et al. 2000). It is imperative that research into the care delivered within clinical neuroscience settings is considered, if the large number of people with brain injuries and neurological conditions are to receive appropriate care. One area with a strong developing research base is that of neuroimaging techniques and neuropsychological assessment which has demonstrated widespread research and concurrent clinical applications (Lezak et al. 2012). With the World Health Organisation recognising that brain injury is fast becoming one of the leading causes of death and disability world-wide (Hyder et al. 2007), more good quality research needs to be conducted.

Much of the extant research in brain injury focuses on traumatic brain injury and either excludes or ignores the wider causes of acquired brain injury. TBI, usually caused by road traffic accidents, but also falls and assaults among others, are themselves heterogeneous in the neurological consequences of the injury, and subsequent impact on the individual. Samples that include a broader range of causes of brain injury, e.g. hydrocephalus, epilepsy, genetic/metabolic disorders, and cerebrovascular diseases, are typically beyond the scope of most research studies. Research into individual disease processes leading to brain injury is plentiful, particularly stroke and epilepsy, but research into less prevalent causes of brain injury attracts less research funding and is therefore less common. Much can be gained by investigating individual causes of brain injury but many commonalities may be being missed by the lack of research looking at the brain injury population as a whole.

The research paper of this thesis (Paper 2) was not specific to TBI, rather the sample included patients with a range of neurological conditions. As one of the wards recruited from included only stroke patients, cerebrovascular disorders were the most common in the sample of patients. Traumatic brain injury comprised a surprisingly small percentage of the sample (16.9%). 27.7% of the sample were not categorised and included a diverse range of 14 different neurological conditions. This clearly
demonstrated the heterogeneity of the sample, particularly in comparison to TBI samples.

Recruiting from a range of clinical neuroscience settings in an acute hospital allowed for the research to include patients with cerebrovascular disease, e.g. stroke, brain tumours, epilepsy and spinal injuries among others. Extensive research literature exists about each of these conditions separately. The strength of this research therefore was that it allowed conclusions to be made about the well-being, person-centred care and cognitive impairment in a sample deemed to be representative of the general neurological patient population.

Critical Appraisal of Paper 1: Systematic Review

The current inclination of researchers is to conduct a systematic, rather than a narrative review (Jesson, Matheson & Lacey, 2011). Choosing to do a systematic review resulted from the choice of topic for the systematic review: Depression following Traumatic Brain Injury (TBI). This research area was chosen out of a need to clarify the research into depression following TBI (Kreutzer, Seel & Gourley, 2001). Although, a number of researchers had previously published narrative reviews in the area (Busch & Alpern, 1998; Moldover, Goldberg & Prout, 2004; Morton & Wheman, 1995) only one systematic review had been conducted on the elderly (Menzel, 2008). The researcher felt it was important to conduct a systematic review that met a research need but also had clear clinical implications.

Search Terms

A necessary but significant limitation of the systematic review was the choice of search terms. The search terms of the systematic review were: depression and brain injury. A number of related terms, such as "psychological morbidity", "mood disorders", "psychiatric disorders“ could have been incorporated. It was determined that expanding the search terms would have resulted in an unmanageable number of studies to review given the time constraints of a doctorate in clinical psychology. The choice was made therefore to keep the systematic review focused in the interest of producing a systematic review that could contribute to the literature on depression following TBI.
The review only included studies from peer-reviewed journals, thus omitting contributions from grey literature to the research question. A large amount of research was excluded because it was not written in English. This reflects the difficulty in conducting a comprehensive systematic review on the prevalence data that could be applied to cultures across the world. It is assumed that developing countries, with their increasing number of cars and associated road-traffic accidents, will increasingly need up-to-date information on the consequences of TBI.

Critical Appraisal Tool

The appropriateness of the critical appraisal tool is essential to the quality of a systematic review (Sanderson, Tatt & Higgins, 2007). Unfortunately a critical appraisal tool suitable for use in the range of studies included in the systematic review was not found. Therefore, the use of a quality assessment tool developed with the specific review question in mind and based on recommendations from research (Moher et al. 2009; Sanderson, Tatt & Higgins, 2007; von Elm et al. 2007), was determined as the most appropriate way to assess the quality of the studies. The development of the quality assessment tool focused on assessing potential sources of bias in the studies, with particular focus on study design and measures of TBI and depression. Studies were scored more highly for the use of; large samples, an appropriate sampling methodology and the use of a control or comparison group.

Clinical Implications

There is still no consensus on a self-report measure of depression following TBI. Seven different self-report measures were used by the fifteen studies included in the systematic review, the most common of which being BDI-II (Beck Depression Inventory-II: Beck et al. 1996) and HADS (Hospital Anxiety and Depression Scale: Zigmond & Snaith, 1983). Although many self-report measures had been validated in traumatic brain injury samples, this was not the case for all measures. Measuring depression following TBI is somewhat complicated by the overlap between depressive symptoms and symptoms of post-concussive syndrome. If depression is to be accurately screened for following brain injury then there is a need for an appropriate tool to use for this purpose. A study comparing measures of depression in a TBI sample would go some way to achieving this goal.
In addition to an accurate tool for measuring depression following brain injury, it is important that health professionals receive appropriate training and information about depression following TBI. If health professionals are unsure about depression following TBI then the person with a brain injury cannot be expected to understand either. The need for health professionals to communicate the message that depression following TBI is common would go a long way to normalising the experience of people with depression following TBI, itself an important therapeutic goal.

Understanding the relationship between brain injury and depression is critical for developing interventions aimed at treating depression in people after a brain injury. There are a number of factors increasing the risk of someone developing depression following TBI. For example, increasing self-awareness following TBI, as part of the recovery process, can have a detrimental impact on the individual’s emotional well-being as they adjust to their situation. Conversely there are factors that make someone resilient to developing depression, e.g. a robust social network and access to a comprehensive rehabilitation programme. Research investigating the factors increasing resiliency in people following TBI would likely inform treatment and rehabilitation programmes for those people with a TBI.

Critical Appraisal of Paper 2: Research Paper

The research paper contributed to the literature around Care Mapping – Neurorehabilitation (DCM-NR), as the use of this is still in its infancy. The research paper also makes a valuable contribution to the evidence in cognitive impairment, dependency and well-being in a neurological population. Prior research into cognitive impairment, dependency and DCM has been conducted in dementia care settings (Edelman, Kuhn & Fulton, 2004; Gigliotti, Jarrott & Yorgason, 2004; Jarrot & Bruno, 2003). Given the impact of brain injury on cognitive functioning, dependency and well-being, it is equally important to conduct research into these factors in clinical neuroscience settings.

Funding

It is noted that training in Dementia Care Mapping was required for this research and the Bradford Dementia Group kindly provided this training free of charge. The Bradford
Dementia Group was not involved in the collection or analysis of data, instead providing their advice and expertise in developing the research methodology and protocol. The support of the Bradford Dementia Group is gratefully appreciated.

Including participants without capacity

Including patients deemed to be lacking in capacity to take part in research is a matter of contention. Although every effort can be made to meet the patient’s best wishes, it cannot be known if these decisions are what the patient would have made. It is important to include those people who may often be excluded from research and may not be able to communicate their opinion. This is especially pertinent given that the research project was investigating the care these people received. Indeed the NHS Ethics board that approved this research project were pleased that those patients lacking capacity were to be included provided the appropriate methods were undertaken to assess capacity. Assessing capacity was a time consuming and yet essential part of the research project that was conducted by the research supervisor who was also a Consultant Clinical Neuropsychologist at the hospital.

Choice of Neuropsychological measure

The use of an appropriate measure of cognitive functioning was a key concern early in the development of the research project. There are a large number of validated and well researched measures used to assess various cognitive function, such as the Wechsler Adult Intelligence Scale - 4th edition (Wechsler, 2008), Behavioural Assessment of Dysexecutive Syndrome (BADS: Wilson et al. 1996), and Rivermead Behavioural Memory Test - 2nd edition (Wilson, Cockburn & Baddeley, 2003) to name a few. The majority of these measures would require a controlled assessment environment and extended periods of time with the patient, both of which are difficult to access in an acute hospital setting. As well as being impractical for hospital settings, detailed cognitive assessment is also tiring for patients and time inefficient for research purposes. Thus it was decided that a screening measure would be most appropriate for the purposes of this research.

To briefly assess the presence of cognitive impairment and the degree of cognitive impairment of participants, three possible measures were identified. The general cognitive screening tool from the Wechsler Memory Scale – 4th Edition (WMS-IV:
Wechsler, 2009) was not chosen due to the cost of the WMS-IV. The remaining two measures were both designed as dementia screening measures: Mini-mental State Examination (MMSE: Folstein, 1975), and Addenbrooke’s Cognitive Examination Revised (ACE-R: Mioshi et al. 2006). Of the two, the ACE-R was chosen because it covered a wider range of cognitive functions, incorporated all items from the MMSE and had previously demonstrated good validity in a brain injury sample (Gaber, 2008).

Despite showing good validity in TBI samples, the ACE-R has mixed results in its effectiveness as a cognitive screening measure in stroke patients (Morris, Hacker & Lincoln, 2012; Pendlebury et al. 2012). Both studies reported that the ACE-R was still more accurate at determining cognitive impairment than MMSE in patients following a stroke. Morris et al. (2012) reported that the ACE-R was adequate in detecting some areas of cognitive impairment, visuospatial, attention and executive function but did not screen for overall cognitive impairment with acceptable levels of specificity or sensitivity. In contrast, Pendlebury et al. (2012) demonstrated that the ACE-R had good sensitivity (83%) and specificity (73%) in detecting mild cognitive impairment in patients following stroke. Due to the lack of a better measure for screening cognitive impairment following stroke the ACE-R was used; however, the development of a cognitive screening measure for use in a range of neurological conditions, including stroke, is of clinical importance.

The administration of the ACE-R in an acute hospital setting raised a number of difficulties. All cognitive assessments had to be conducted at the patient’s bedside, often in a busy ward environment as there were no quiet areas available. Distractions, particularly in patients with potential impairments of attention, would have a negative impact of their performance. Distractions were minimised by closing the curtains around the patient’s bed (with their permission) and by checking that there was appropriate time before any activities or medical/personal care were scheduled. Despite the best efforts of the researcher distractions during assessment were common. Another difficulty with the ACE-R was that some patients were not able to complete some items due to a physical impairment, e.g. hemiparesis, or a sensory impairment, e.g. blindness. Despite these limitations the ACE-R provided a suitable measure of cognitive impairment with minimal burden on the patient.

Copyright Issues pertaining to ACE-R
When developing the research methodology and deciding on a cognitive assessment measure, the Addenbrooke’s Cognitive Examination was freely available to use. Although not the only reason, this had a significant impact on choosing this measure for the research. Part way through data collection the researchers were made aware that the ACE-R was to no longer be used, for clinical or research purposes. Several items of the ACE-R were identical to items from the Mini-Mental State Examination (MMSE: Folstein et al. 1975) thus considered to infringe upon the copyright of MMSE, which was being published by PAR.

Initially, PAR were contacted by a member of the research team to seek clarification on this issue. As data collection had already begun, with approximately 50% of data already collected, PAR were sympathetic to the situation and voiced no immediate objection to continuing data collection using the ACE-R, although they could not officially condone its use.

In considering the best course of action there were three options available to complete the research, A) continue using ACE-R, B) use the newly developed, and free to use, Addenbrooke’s Cognitive Examination – 3rd edition (ACE-III) for the remainder of data collection, C) re-assess all participants using the ACE-III.

The ACE-III replaced items of the ACE-R that infringed the copyright of the MMSE with similar items. The ACE-III had not been validated in a brain injury population, as ACE-R had been (Gaber, 2008), and suitable cut-off scores for mild-cognitive impairment, had not been determined. The inter-test reliability between ACE-R and ACE-III had not been published at the time this decision was being made. The use of the ACE-III, a measure not yet validated in the sample population, may have introduced a significant confounding factor to the research.

Reassessing cognitive impairment of those participants who had already completed the ACE-R was not possible due to a number of reasons. It was deemed a second cognitive assessment would constitute an excessive burden purely for research purposes. It was also essential that cognitive impairment be measured contemporaneously with the DCM data for the relationship to be accurately measured. A large number of participants who had already completed the ACE-R had been discharged and reassessing those would have been unfeasible.

The decision was made to proceed collecting data using the ACE-R, in the absence of any specific indication to the contrary by PAR, and allocate money from the budget for any costs of using the ACE-R if this became necessary.
Severity of TBI

The typical methods used, clinically and in research, to indicate severity of traumatic brain injury were largely inappropriate for the participants of this research study. Although there is routine use of neuroimaging following a brain injury, behavioural measures remain the primary source of measuring severity of TBI. Glasgow Coma Scale (GCS), length of time in post-traumatic amnesia (PTA) and length of loss of consciousness (LOC) are routinely used to classify severity of injury sustained as mild, moderate, and severe (Lezak et al. 2012). The same indicators of severity in TBI do not necessarily apply to those with an acquired brain injury where the mechanism of injury may not yield the same behavioural outcomes. The majority of patients, having not suffered a traumatic brain injury, did not have a GCS score or length of PTA or LOC recorded in their medical records.

Care Mapping - Neurorehabilitation

In conducting the research project, DCM-NR appeared to be an acceptable method, to staff and patients, and to be a useful tool in measuring patient’s person-centred care. Previous research supports this, as DCM-NR has been demonstrated to be feasible, valid and acceptable as a measure of person-centred care (McIntosh et al. 2012; O’Hanlon et al. In Preparation; Westbrook et al. 2013). The use of such a tool, following appropriate training by the Bradford Dementia Group, ensured the quality of this aspect of the research project.

The adaptations made to DCM in producing Care Mapping Neurorehabilitation (DCM-NR) for use in clinical neuroscience settings were appropriate. There were no major difficulties with assigning behaviour category codes or well-being values at each time-frame. Furthermore, the addition of certain codes to reflect the inpatient setting where medical care is prevalent and curtains could be closed around the hospital bed were particularly valuable and frequently used. The use of three-minute timeframes and of a single mapper-per-bay did not appear to detract from the ability to measure person centred care in this study.

DCM-NR is both a measure of person-centred care and as a process for promoting person-centred care to improve the well-being of patients. The research project largely focused on DCM-NR as a measure or tool, and its links to cognitive impairment and
dependency, in accurately measuring well-being and person-centred care. This research did not investigate the equally important questions about the whether the process of DCM-NR is effective in clinical neuroscience settings. The need to enhance DCM-NR as a process was especially pertinent given the difficulties and challenges of applying DCM-NR in a hospital setting that were identified when conducting the research.

**Selection Bias**

Participants were chosen by convenience sampling. Wards were comprised of bays and those with the most number of occupied beds were chosen to maximise the amount of data that could be collected from each round of mapping. This typically resulted in larger seven bed bays, occupied by men, being chosen. 72.3% of participants in the research study were male. How this compares to the general population of males in the clinical neuroscience population in the hospital was unknown.

The time chosen to map the bays may have also introduced bias to the results. The time chosen to map was either 8.30am to 12.30pm or, 1pm to 4pm so that a meal-time could be observed as well as a period of rest afterwards. Staff did indicate that the time observed, was generally representative of the day as a whole and this is supported by research into DCM (Fossey, Lee & Ballard, 2002; Fulton, Edelman & Kuhn, 2006). However, staff fed back that evening shifts on the wards are very different from shifts during the day, and suggested that mapping in the night might yield different results. Research was not conducted in the evening or night-time so that the time mapped was consistent across the wards, and the suggestion of investigating person-centred care during night-time shifts was considered a future clinical use of DCM-NR.

As per DCM-NR guidelines (Bradford Dementia Group, 2012) sampling could only occur in communal bays, patients in single bed rooms who are clearly at risk of being more isolated, were not included in the research. Also patients were largely free to move out of the communal bays being mapped, often for extended periods of time, e.g. for physiotherapy. The use of a single mapper per bay prevented mapping patients during activities off the ward, as recommended by McIntosh et al. (2012) and Westbrook et al. (2013); however, by researching two bays separately instead of one bay together, twice as much mapping data was collected. This decision was made following consultation with researchers at the Bradford Dementia Group with the aim of
maximising the efficiency of the research and strengthening the conclusions of the research.

Conducting research in a hospital setting

Acute hospital wards are highly stressed and busy environments and research in such environments can be challenging. The needs of patients on hospital wards can be complex and demanding, particularly on clinical neuroscience wards where patients can present with complex physical and cognitive rehabilitation needs and behaviour that staff can find challenging. Ward staff invariably have large amounts of tasks to juggle in providing care to the patients on the ward. For this reason it is especially important to ensure that the patients in these settings are receiving person-centred care.

Large numbers of ward staff, including bank staff, on differing shifts made explaining the research to staff problematic. The senior ward staff were instrumental in ensuring that all staff on shift were aware of the research being conducted. Feeding back the care mapping results, was equally difficult as a) space on the ward to feedback to 10 or more staff was rare and b) staff were largely unable to stop their duties to attend feedback sessions. The small numbers of staff who were able attend feedback sessions were usually not the staff who had been observed during the mapping process. The lack of follow-up, following feedback sessions, to staff would have a detrimental effect on the staff implementing the feedback into their everyday work.

The professions of staff attending feedback sessions were usually nurses and, less frequently, therapy staff, while doctors were absent. Clearly there is a need to communicate person-centred care across the range of professions in a hospital setting to ensure the message is consistent. The process of DCM-NR still needs to be adapted to be more effective in hospital settings. If care mapping was a regular process, and involved investment from the hospital, then these difficulties could be minimised.

Alternative methods of feeding back the results could be considered. All staff members who attended the feedback sessions were given out leaflets summarising the main feedback points, what was done well and what could be done better. In addition the ward specific report and copies of these leaflets were left for other staff to view or collect at their leisure. The possibility of creating posters, summarising the main points, for display on the wall was discussed if future care mapping were to take place on the wards.
Person-centred care

In the wake of the inquiry into patient care resulting in the Mid Staffordshire National Health Service (NHS) Foundation Trust Inquiry (Francis, 2013), the need to improve patient care in hospitals has been highlighted in the UK. Although only mentioning person-centred care in relation to the care of older adults, the UK government’s response to the inquiry (Department of Health, 2013) explicitly stated the need for patients to be put at the forefront of their care.

In completing data collection and feeding back the results of DCM-NR data to the staff teams it was pleasing to note that the majority of the time patients received good, person-centred care. There were very few instances of staff-patient interactions that appeared to have a detrimental effect on the patient’s well-being. The process of care mapping and the feeding back of this was generally well received both by ward staff and ward managers.

Person-centred care has long been recognised as being of central importance to dementia care services. With Kitwood’s work (1997) and the development of DCM by the Bradford Dementia Group, person-centred care is being advanced in dementia care services. There is a need for person-centred care to be delivered to not just those with dementia, and recent reports into the care of people with learning disabilities (Department of Health, 2012) and patients in hospitals (Francis, 2013) demonstrate the need for person-centred care to be expected for people, of all ages, receiving care. Given the findings of the Mid Staffordshire NHS Foundation Trust Inquiry (Francis, 2013), there appears to be potential for DCM-NR, as an evidenced based method, to be utilised in promoting and improving person-centred care.

Future Research Considerations

Future directions for research into DCM-NR should focus on evaluating and improving the effectiveness of the process of DCM-NR. A longitudinal study into the effectiveness of DCM-NR, through repeated mapping to track changes in patient well-being and person-centred care, would be a possible first step in investigating this. Numerous studies into the process of DCM in dementia care settings have shown DCM to be effective in improving patient well-being and person-centred care (Brooker et al. 1998; Martin & Younger 2001) or reducing agitation and distress (Chenoweth et al. 2009).
Early on in the research process this was considered as a possible research project; however, it was ultimately deemed unfeasible to do two rounds of mapping, around six months apart, on six wards, with feedback for each ward on both rounds, in the time frame allowed for a Doctorate in Clinical Psychology thesis.

Measuring the efficacy of feedback sessions to promote change in care practice would be key to researching DCM-NR as a process. Given the difficulty with feeding back to staff, staff could be followed up with an interview or questionnaire 3-6 months after receiving feedback to determine what, if any, changes to their professional practice they had taken on. Varying the length, content and format of feedback sessions would help further investigate the best way to disseminate the DCM-NR feedback information, to maximise the potential for improving person-centred care.

A major finding of the research project was that those patients with severe cognitive impairment and high levels of dependency were less likely to be in well-being or engaging in meaningful activity. In feeding back to staff it was clear that staff interacted less with those patients who were more impaired. This is not unsurprising given that such patients are less able to respond to staff interactions, especially humour. A goal for future research would therefore be to develop and evaluate methods of improving well-being in patients and people who are severely cognitively impaired and who are dependent on others to access activities that could improve their well-being.

The systematic review raises the importance of depression following TBI; therefore, a potential study could look at measuring depression alongside care-mapping neurorehabilitation. This could determine whether DCM-NR and person-centred care affects levels of depression in the case of a longitudinal study. Alternatively a cross sectional study could determine whether depression impacts upon well-being scores, behaviours observed and staff-patient interactions from DCM-NR.

Conclusion

Overall, the research paper and systematic review contributed to the respective areas of literature. The two papers highlighted the importance of depression, cognitive impairment, dependency and person-centred care in the clinical neuroscience population. Both the research paper and systematic review will be submitted to the journal of Neuropsychological Rehabilitation for publication.
It is important that research has both clinical and research implications that inform developments in the chosen field. Given the prevalence of neurological disorders and brain injuries in modern societies, and resultant challenges to well-being, care-mapping neurorehabilitation remains an important tool to improving the well-being of those with brain injuries and neurological conditions.
References


Appendix 1: Submission Guidance for Neuropsychological Rehabilitation

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**Manuscript preparation**

1. **General guidelines**

   - Papers are accepted only in English. British English spelling and punctuation is preferred. Any consistent spelling style may be used. Please use double quotation marks, except where “a quotation is ‘within’ a quotation”.
   - There is no word limit for manuscripts submitted to this journal. Authors should include a word count with their manuscript.
   - Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgments; appendixes (as appropriate); references; table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
   - Abstracts of 150-200 words are required for all papers submitted. Avoid abbreviations, diagrams, and references to the text in the abstract.
   - Each paper should have 5 [keywords](http).
   - Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](http).
   - All the authors of a paper should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. The affiliations of all named co-authors should be the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the article is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
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For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms should not be used.
Authors must adhere to SI units. Units are not italicised.
When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
Authors should supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Section headings should be concise and should not contain numbering.
Acknowledgements should be gathered into a brief statement at the end of the text. All sources of financial sponsorship are to be acknowledged, including the names of private and public sector sponsors. This includes government grants, corporate funding, trade associations and contracts.
Tables should be kept to the minimum. Each table should be typed double spaced on a separate page, giving the heading, e.g., "Table 2", in Arabic numerals, followed by the legend, followed by the table. Make sure that appropriate units are given. Instructions for placing the table should be given in parentheses in the text, e.g., "(Table 2 about here)".
Results of statistical tests should be given in the following form: "... results showed an effect of group, $F(2, 21) = 13.74, \text{MSE} = 451.98, p < .001$, but there was no effect of repeated trials, $F(5, 105) = 1.44, \text{MSE} = 17.70$, and no interaction, $F(10, 105) = 1.34, \text{MSE} = 17.70$."

Other tests should be reported in a similar manner to the above example of an F-ratio. For a fuller explanation of statistical presentation, see the APA Publication Manual (6th ed.).

Abbreviations that are specific to a particular manuscript or to a very specific area of research should be avoided, and authors will be asked to spell out in full any such abbreviations throughout the text. Standard abbreviations such as RT for reaction time, SOA for stimulus onset asynchrony or other standard abbreviations that will be readily understood by readers of the journal are acceptable. Experimental conditions should be named in full, except in tables and figures.

2. Style guidelines

- **Description of the Journal’s reference style**
- **Guide to using mathematical symbols and equations**

3. Figures

- It is in the author's interest to provide the highest quality figure format possible. **Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.**
- Figures must be saved separate to text. Please do not embed figures in the paper file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
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- Information about supplemental online material

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- Click here for Information regarding anonymous peer review

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Appendix 2: Northwick Park Dependency Scale

Northwick Park Dependency Scale

Note: Copies of the NPDS and instruction manual can be obtained from Lynne Turner-Stokes, Regional Rehabilitation Unit, Northwick Park Hospital, Watford Road, Harrow, Middlesex HA1 3 U J, U K.

For each item, circle the highest score that applies and answer any additional questions.

1) Mobility Dependency score
   - Walks fully independently 0
   - Independent in electric/self-propelled chair 1
   - Walks with assistance/supervision of one 2
   - Uses attendant-operated wheelchair 3
   - Bed-bound (unable to sit in wheelchair) 4

2) Bed transfers
   - Fully independent 0
   - Requires help from one person 1
   - Requires help from two people 2
   - Requires hoisting by 1 person and takes <1/2 hour 3
   - Requires hoisting by two people and takes <1/4 hour 3

3) Toileting
   - How many times do they need to pass urine during the day? ......
   - How many times do they need to pass urine during the night? ......

3.1) Toileting: bladder
   (Includes getting there, transferring on to toilet, cleaning themselves, adjusting clothing, and washing hands afterwards. If using bottle: includes reaching for it, positioning and replacing it unspilt.)
   - Able to empty bladder independently 0
   - Set-up only (e.g. cope if bottles left within reach) 1
   - Has in-dwelling catheter/convee 1
   - Needs help from 1, and takes <1/4 hour 2
   - Needs help from 1, and takes more than 1/4 hour 3
   - Takes more than 1/2 hour or Needs help from 2 4

3.2) Urinary incontinence
   - No accidents or leakage from catheter/convee 0
   - Continent if toiletted regularly. Occasional accidents 1
   - 1–2 episodes of incontinence/leakage in 24 hours 2
   - 3 episodes of incontinence/leakage in 24 hours 3
   - If scored 1: How often per week? .........
   - If scored 3: How often per day? .........

4) Opening bowels (or emptying colostomy bag)
   - How many times do they open their bowels per day? .........
   - or per week? ........

4.1) Toileting: bowels
   (Includes getting to and transferring on to toilet, cleaning themselves, adjusting clothing, and washing hands afterwards. If has colostomy, includes emptying/changing bag hygienically.)
   NB: Do not include faecal incontinence here.
   - Able to empty their bowels independently 0
   - Set-up only (e.g. giving suppositories/enema) 1
Needs help/supervision from 1, and takes <1/4 hour 2
Needs help from 1, and takes more than 1/4 hour 3
Needs help from 2, and takes <1/4 hour 4
Needs help from 2, and takes more than 1/4 hour 5

4.2) Faecal incontinence
No faecal accidents 0
Requires regular bowel regimen in order to remain continent 1
Occasional faecal accidents (less than daily) 2
Regular incontinence of faeces 3
If has faecal accidents: How often per week?..........

5) Washing and grooming
(Includes washing hands and face, cleaning teeth, brushing hair, and shaving or make-up.)
*NB: This item does not include bathing/showering.*
Able to wash and groom independently 0
Needs help to set up only (e.g. laying out things, filling bowl with water) 1
Needs help from 1, and takes <1/2 hour 2
Needs help from 1, and takes more than 1/2 hour 3
Needs help from 2, and takes <1/2 hour 4
Needs help from 2, and takes more than 1/2 hour 5
Note: It is very rare to need help from 2 to wash unless patient requires restraint

6) Bathing/showering
(Includes getting to bath/shower-room, transferring in and out, washing and drying.)
*NB: If unable to bath or shower, complete as for thorough stripwash.*
Able to have bath/shower independently 0
Needs help to set up only (e.g. running bath, soaping flannel, etc.) 1
Needs help from 1, and takes <1/2 hour 2
Needs help from 1, and takes more than 1/2 hour 3
Needs help from 2, and takes <1/2 hour 4
Needs help from 2, and takes more than 1/2 hour 5
Northwick Park Dependency Score 317

7) Dressing
(Includes putting on shoes, socks, tying laces, putting on splint or prosthesis.)
Able to dress independently 0
Needs help to set up only (e.g. laying out clothes)
or Needs incidental help from 1 (e.g. just with shoes) 1
Needs help from 1, and takes <1/2 hour 2
Needs help from 1, and takes more than 1/2 hour 3
Needs help from 2, and takes <1/2 hour 4
Needs help from 2, and takes more than 1/2 hour 5

8.1) Eating
*Entirely gastrostomy/nasogastric fed – go to 8.30*
Able to eat independently 0
Needs help to set up only (e.g. opening packs or passing special cutlery) 1
Needs help from 1, and takes <1/2 hour 2
Needs help from 1, and takes more than 1/2 hour 3

8.2) Drinking
*Entirely gastrostomy/nasogastric fed – go to 8.30*
Able to pour own drink and drink it independently 0
Able to drink independently if left within reach 1
Needs help or supervision, and takes <1/2 hour 2
Needs help or supervision, and takes >1/2 hour 3
8 . 3 ) Enteral feeding (gastrostomy or nasogastric tube)

<table>
<thead>
<tr>
<th>No enteral feeding</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to manage feeds entirely independently</td>
<td>0</td>
</tr>
<tr>
<td>Needs help to set up feed just once a day/night</td>
<td>1</td>
</tr>
<tr>
<td>Needs help to set up feed twice a day</td>
<td>2</td>
</tr>
<tr>
<td>Needs help to set up feed three times a day</td>
<td>3</td>
</tr>
<tr>
<td>Needs help to set up feeds or give extra flushes during the night</td>
<td>4</td>
</tr>
</tbody>
</table>

9 ) Skin pressure relief

| Skin intact and able to relieve pressure independently | 0 |
| Needs prompting only to relieve pressure | 1 |
| Skin intact, needs help from 1 to turn (4 hourly) | 2 |
| Skin intact, needs help from 2 to turn (4 hourly) | 3 |
| Skin marked or broken, needs 1 to turn (2 hourly) | 4 |
| Skin marked or broken, needs 2 to turn (2 hourly) | 5 |

10 ) Safety awareness

| Fully orientated, aware of personal safety | 0 |
| Requires some help with safety and orientation but | |
| Safe to be left for >2 hours and could summon help in emergency | 1 |
| Requires help to maintain safety | |
| Could not be left for 2 hours and could not summon help in an emergency | 2 |
| Requires constant supervision | 3 |

11 ) Communication

| Able to communicate all needs | 0 |
| Able to communicate basic needs without help | 1 |
| Able to communicate basic needs with a little help/using communication aid | 2 |
| Able to respond to direct questions about basic needs | 3 |
| Unable to understand questions, but responds to gestures/contextual cues | 4 |
| No effective means of communication | 5 |

12 ) Behaviour

| Compliant and socially appropriate | 0 |
| Needs verbal/physical prompting for daily activities | 1 |
| Needs persuasion to comply with rehabilitation or care | 2 |
| Needs structured behavioural modification programme | 3 |
| Disruptive, inclined to aggression | 4 |
| Inclined to wander off ward/out of house | 5 |

13 ) Total Basic Care Needs Total

14 ) Special Needs: add 5 for each of the below

| A) Tracheostomy | 5 |
| B) Open pressure sore/wound requiring dressings | 5 |
| C) >2 interventions required at night | 5 |
| D) Patient or relatives need substantial psychological support | 5 |
| E) Requires isolation (e.g. for MRSA (multiply resistant Staphylococcus aureus) screening/colonization) | 5 |
| F) Intercurrent medical/surgical problem | 5 |
| G) Needs one-to-one ‘specialising’ | 5 |

15 ) Total Special Nursing Needs Total

16 ) Total dependency Total
# Appendix 3: Addenbrooke’s Cognitive Examination – Revised

## Addenbrooke’s Cognitive Examination - ACE-R

*Final Revised Version A (2005)*

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date of Testing: ...... /...... /......</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth:</td>
<td>Tester’s Name:------------------------</td>
</tr>
<tr>
<td>Hospital No.:</td>
<td>Age at Leaving Full-time Education:-----------------</td>
</tr>
<tr>
<td></td>
<td>Occupation:--------------------------</td>
</tr>
<tr>
<td></td>
<td>Handedness:-------------------------</td>
</tr>
</tbody>
</table>

### Orientation

- **Ask: What is the Day**
  - [Score 0-5]

- **Ask: Which Building**
  - [Score 0-5]

### Registration

- Tell: "I’m going to give you three words and I’d like you to repeat after me: lemon, key and ball. After subject repeats, say ‘Try to remember them because I’m going to ask you later.’ Score only the first trial (repeat 3 times if necessary).

### Attention & Concentration

- Ask the subject: ‘could you take 7 away from a 100? After the subject responds, ask him or her to take away another 7 to a total of 5 subtractions. If subject makes a mistake, carry on and check the subsequent answer (i.e. 93, 84, 77, 70, 03-score 4)

  Stop after five subtractions (93, 85, 78, 72, 65).

- **Ask:** ‘Could you please spell WORLD for me? Then ask him/her to spell it backwards:

### Memory - Recall

- **Ask:** ‘Which 3 words did I ask you to repeat and remember?’

### Memory - Anterograde Memory

- Tell: ‘I’m going to give you a name and address and I’d like you to repeat after me. We’ll be doing that 3 times, so you have a chance to learn it. I’ll be asking you later’

  Score only the third trial

<table>
<thead>
<tr>
<th>Name</th>
<th>1st Trial</th>
<th>2nd Trial</th>
<th>3rd Trial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harry Barnes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>73 Orchard Close</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kingsbridge</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Devon</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Memory - Retrograde Memory

- Name of current Prime Minister
- Name of the woman who was Prime Minister
- Name of the USA President
- Name of the USA President who was assassinated in the 1960’s

---

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**VERBAL FLUENCY - Letter 'P' and animals**

- **Letters**
  - Say: 'I'm going to give you a letter of the alphabet and I'd like you to generate as many words as you can beginning with that letter, but not names of people or places. Are you ready? You've got a minute and the letter is P.'

- **Animals**
  - Say: 'Now can you name as many animals as possible, beginning with any letter?'

---

**LANGUAGE - Comprehension**

- **Show written instruction:**

**Close your eyes**

---

**LANGUAGE - Writing**

- **3 stage command:**
  - 'Take the paper in your right hand. Fold the paper in half. Put the paper on the floor'

- **Ask the subject to make up a sentence and write it in the space below:**
  - Score 1 if sentence contains a subject and a verb (see guide for examples)
LANGUAGE - Repetition

➢ Ask the subject to repeat 'hippopotamus'; 'eccentricity'; 'unintelligible'; 'statistician'. Score 2 if all correct; 1 if 3 correct; 0 if 2 or less.

➢ Ask the subject to repeat: 'Above, beyond and below'

➢ Ask the subject to repeat: 'No ifs, ands or buts'

LANGUAGE - Naming

➢ Ask the subject to name the following pictures:

- Pencil
- Watch
- Kangaroo
- Anchor
- Camel
- Barrel
- Penguin
- Rhinoceros
- Accordion

LANGUAGE - Comprehension

➢ Using the pictures above, ask the subject to:
  - Point to the one which is associated with the monarchy
  - Point to the one which is a marsupial
  - Point to the one which is found in the Antarctic
  - Point to the one which has a nautical connection
LANGUAGE - Reading

- Ask the subject to read the following words: (Score 1 only if all correct)
  - sew
  - pint
  - soot
  - dough
  - height

VISUOSPATIAL ABILITIES

- Overlapping pentagons: Ask the subject to copy this diagram

![Overlapping pentagons](image)

- Wire cube: Ask the subject to copy this drawing (for scoring, see instructions guide)

![Wire cube](image)

- Clock: Ask the subject to draw a clock face with numbers and the hands at ten past five.
  (for scoring see instruction guide: circle = 1, numbers = 2, hands = 2 if all correct)

![Clock](image)
Ask the subject to count the dots without pointing them.

[Score 0-4]
**RECALL**

- Ask "Now tell me what you remember of that name and address we were repeating at the beginning."

<table>
<thead>
<tr>
<th>Harry Barnes</th>
<th>73 Orchard Close</th>
<th>Kingsbridge</th>
<th>Devon</th>
</tr>
</thead>
</table>

*Score 0-7*

**RECOGNITION**

- This test should be done if subject failed to recall one or more items. If all items were recalled, skip the test and score 5. If only part is recalled start by ticking items recalled in the shadowed column on the right hand side. Then test not recalled items by telling "ok, I'll give you some hints: was the name X, Y or Z?" and so on. Each recognised item scores one point which is added to the point gained by recalling.

<table>
<thead>
<tr>
<th>Jerry Barnes</th>
<th>Harry Barnes</th>
<th>Harry Bradford</th>
</tr>
</thead>
<tbody>
<tr>
<td>37 Oakhampton</td>
<td>73 Kingsbridge</td>
<td>76 Darlington</td>
</tr>
<tr>
<td>Orchard Place</td>
<td>Dorset</td>
<td>recalled</td>
</tr>
<tr>
<td>recalled</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Score 0-5*

**General Scores**

- MMSE /30
- ACE-R /100

**Subscores**

- Attention and Orientation /18
- Memory /26
- Fluency /14
- Language /16
- Visuospatial /16

Normative values based on 63 controls aged 52-75 and 142 dementia patients aged 46-86

Cut-off <88 gives 94% sensitivity and 80% specificity for dementia

Cut-off <82 gives 84% sensitivity and 100% specificity for dementia
Participant Information Sheet: Patients

Improving patient care and well-being

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. A member of the research team will go through this information sheet with you. We suggest this will take about 15 minutes.

What is the purpose of the study?

This project is about testing a method to check and improve care for patients like yourself on the ward. This project is being carried out by researchers from the University of Manchester (Katie O’Hanlon and Andrew Leigh) and also Dr. Russell Sheldrick. The study will form part of two Doctorates in Clinical Psychology for the researchers from the University of Manchester.

What will the study involve?

It will involve two researchers observing a bay on the ward. The researcher will write a few notes about what you and staff are doing. You and staff will not be required to do anything differently. They will not watch any personal care. The observations will help identify how good the care is, what you do with your day, and what could be improved.

What will I have to do?

When the researchers observe the ward, you are not required to do anything differently. Each ward bay will be observed for 4 hours, where you can do whatever you usually do. After the observation, one of the researchers may ask to speak to you on the ward. If preferred the researcher can speak to you in a nearby private area to ensure privacy and confidentiality. This will take no more than 30
minutes. This will help us find out about your experiences of the observations taking place. The researcher will write down what you tell them and if you agree it will be recorded on audio-tape. This information will be confidential to the research team. If you decide you do not want to speak to the researcher, you do not have to. A researcher will also meet with you to complete a measure of your cognitive abilities, this will take about 20 minutes. If preferred the researcher can complete this measure with you in a nearby private area to ensure privacy and confidentiality. This will involve you answering a series of questions. Again, if you decide you do not want to complete this you do not have to.

**What are the benefits of taking part?**

It is hoped that this will help to improve the care for other people who may be admitted onto this ward in the future. It may also improve your care on the ward.

**What are the possible risks of taking part?**

No major risks have been identified for being observed in this way. However, you may find that being observed is distressing. If this happened, you could ask us (or a member of staff to tell us) to stop, and we will leave. Alternatively, if we observe you becoming distressed as a result of the observation, we will stop and leave. Similarly, if you become distressed during the interview or while measuring your cognitive abilities we will stop and leave.

**What will be done with the information we collect?**

We will write a report on the research, which may also be published in a research journal. All information will be kept confidential. It will not use anyone’s name. We will keep the data we collect for up to 10 years at the University of Manchester in a secure location. It will be destroyed after this time. If you wish to be informed of the research results, the researcher will contact you at the end of the study.

**Do I have to take part?**

It is your decision to take part. If you don’t want to, that is alright. You do not have to give a reason if you do not want to take part. If you start and decide you want to stop, you are free to do so. Whatever you decide, this will not affect the care you receive on the ward.

**Will anyone be informed if I do decide to take part?**

If you do decide to take part, the health care professional currently responsible for your care, or alternatively your GP, will receive a short letter informing them that you have consented to take part in the above study. They will not be informed of any other details of your involvement. If you inform us that you or anyone else is at risk, we may need to share this information with staff on the ward or the professional currently responsible for your care, but we would discuss this with you at the time if this occurred.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by an NHS Research Ethics Committee.

**What if there is a problem?**
If you have a concern about any aspect of this study, you should ask to speak to one of the researchers who will do their best to answer your questions [01613060402]. If you remain unhappy and wish to complain formally, to make a complaint, you can contact a University Research Practice and Governance Coordinator on the following details:

Tel: 0161 2757583 or 0161 2758093

Email: research-governance@manchester.ac.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Manchester, but you may have to pay for your legal costs.

The normal National Health Service complaints mechanisms will still be available to you.

Where can I get more information?

If you have any concerns or questions, please talk to a nurse, Russell Sheldrick on the ward, or Katie/Andrew, on 01613060402.

We would like to give you some time to think about whether you are happy to be involved, so either Katie or Andrew will come back and ask for your decision in a day or so. If you are happy to participate you will be asked to sign a consent form.

Thank you very much for considering taking part in our research. Please discuss this information with your family, friends or the ward team if you wish.
Appendix 5: Staff Consent Form

Miss Katie O’Hanlon/ Mr Andrew Leigh
School of Psychological Sciences
2nd Floor
Zochonis Building
Brunswick Street
Manchester
M13 9PL
Tel: 01613060402
katie.ohanlon@postgrad.manchester.ac.uk
andrew.leigh@postgrad.manchester.ac.uk

Consent form: Staff

Participant identification number :........

Study number :.................................

Title: Improving patient care and well-being
Name of Investigators: Miss Katie O’Hanlon/Mr Andrew Leigh

Please initial the boxes and sign if you are in agreement

1. I confirm that I have read and understood the information sheet dated .............. (version .......) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

3. I agree to take part in the above study.
Appendix 6: Patient Consent Form

Consent form: Staff

Participant identification number :........

Study number :.................................

Title: Improving patient care and well-being

Name of Investigators: Miss Katie O’Hanlon/Mr Andrew Leigh

Please initial the boxes and sign if you are in agreement

1. I confirm that I have read and understood the information sheet dated .............. (version ......) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

3. I agree to take part in the above study.

____________________  _______________  _____________
Name of participant    Date                     Signature

____________________  _______________  _____________
Name of researcher     Date                     Signature
Appendix 7: Assent Form

Consultee Declaration Form

Participant identification number :........

Study number :................................

Title: Improving patient care and well-being

Name of Investigators: Miss Katie O’Hanlon and Mr Andrew Leigh

Please initial the boxes and sign if you are in agreement

1. I (name of close relative or friend) have been consulted about (name of potential participant)'s participation in this research project and have read the consultee information sheet dated .......... (version ....). I have had the opportunity to ask questions about the study and understand what is involved. I agree to their taking part in this research.

2. I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without their care or legal rights being
affected.

3. I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from the University of Manchester or from regulatory authorities where it is relevant to their taking part in this research.

4. I agree to their the following being informed of their participation in the study:
   - GP
   - other care professional

5. I agree that the interview can be audio-recorded and direct quotes from this interview can be used in reporting of the research. I understand that any personal details will not be identified.

____________________  ____________  ____________
Name of participant  Date                  Signature

____________________  ____________  ____________
Name of researcher   Date                  Signature
Care Mapping-Neurorehabilitation

Report for Ward ..., Salford Royal Infirmary

Thanks to all staff and patients on Ward ..., Salford Royal Infirmary, for welcoming the mappers and for conducting your work as usual during the mapping. We do appreciate that being observed can be an anxiety provoking experience for staff.

... is a ... ward providing specialist care for people with a variety of acute brain injuries. As such it caters for a diverse group of patients, including those who are highly dependent for the care needs and those who are more independent. This creates challenges for staff to provide person centred care when patients have a diversity of both rehabilitation and medical care needs. The tool, Care Mapping-Neurorehabilitation (DCM-NR), is being used on this ward as part of a research study to investigate the feasibility of this tool for use in a range of neuroscience settings.

There were four maps (observations) carried out on the ward in total (each for a two-and-a-half hour period) on ... and ... There were four patients present on each of the maps, with the exception of the map carried out on ..., where there were only three. As such, a total of 15 patients were observed. There were a number of different staff members on shift at the time of the various maps. Staff and patients will not be named in this report to maintain confidentiality.

If you have any questions about DCM-NR or the data in this report, please do not hesitate to contact us:

Katie O’Hanlon
Trainee Clinical Psychologist

Andrew Leigh
Trainee Clinical Psychologist

Dr Russell Sheldrick
Consultant Clinical Neuropsychologist

THIS REPORT IS CONFIDENTIAL TO THE WARD- TEAM AND ITS MAPPERS
What is Care Mapping-Neurorehabilitation?

Dementia Care Mapping-Neurorehabilitation is an observational tool and a process, which was designed to help staff to consider and improve the quality of care for people in neurorehabilitation settings. When carrying out observations or a ‘map’, Dementia Care Mappers will observe between one and eight people with dementia. What they write down attempts to capture the experience of care from the perspective of the person with a neurological condition.

The mappers observe people continuously for a number of hours. Every three minutes a mapper writes down a Behaviour Category Code (BCC) which represents what each person was mainly doing for that five minute period. This is chosen from a list of 24 codes which are denoted by a letter (e.g. F= eating and drinking, L= leisure, fun and recreational activities). In each three minutes the mapper also records a Mood and Engagement (ME) Value, which represents how engaged the person is and whether their mood is positive or negative. This is represented on a six point scale (+5, +3, +1, -1, -3, -5).

The mapper also has a way of capturing the quality of interactions with staff for each person they are observing through Personal Detractions and Personal Enhancers. Personal Detractions are times when an interaction ‘puts down’ a patient and undermines one or more of their psychosocial needs of comfort, attachment, identity, occupation and inclusion. For example, talking about him/her in his/her presence as if they were not there would be recorded as ‘ignoring’ and would undermine a person’s psychosocial need for inclusion.

Personal Enhancers are times when a member of staff interacts with a person in a way which has the potential to uphold one or more of her/ his psychosocial needs. For example, providing a patient with verbal support in order to complete an action independently would be coded as ‘enabling’ and would support a person’s need for occupation. Personal Enhancers and Detractions are recorded as and when they occur.

Once the observation is complete the mappers analyse the date they have recorded and put it into a condensed and understandable format. It is that data which is included in this report.
The majority of the time mapped was spent in neutral or positive Mood or Engagement (86.9%).

13.1% of the time mapped was spent in a state of slight negative mood or disengagement but 0% in considerable negative mood.

20.6% of the time mapped was spent in considerable positive Mood or Engagement and 0.4% in high levels of positive Mood or Engagement.

**Scale of Mood and Engagement (ME)**

+5 Exceptionally positive Mood or Engagement – it is hard to envisage anything better: very absorbed or deeply engrossed and/ or very happy and buoyant.

+3 Considerable signs of positive Mood or Engagement: concentrating but distractible and/ or content, happy and relaxed.

+1 Alert and focused on surroundings with no signs of positive or negative mood.

-1 Small signs of negative mood and/ or disengaged and withdrawn.

-3 Considerable signs of negative mood: anxiety, distress or anger.

-5 Extremes of negative mood: apathy, withdrawal, rage, grief or despair.

---
**Group Data: Behaviour Category Codes**

![Group Behaviour Category Code Profile](chart)

### List of Behaviour Category Codes

- **A** Articulation: Interacting with others
- **B** Borderline: Being socially involved, but passively
- **C** Cool: Being socially uninvolved, withdrawn
- **D** Doing for self: Engaging in self care
- **E** Expression: Engaging in an expression or creative activity
- **F** Food: Eating, drinking
- **G** Going back: Reminiscence and life review
- **I** Intellectual: Activity prioritising intellectual abilities
- **J** Joints: Engaging in exercise or physical sports
- **K** Kum and go: Independent walking, standing, moving
- **L** Leisure: Engaging in leisure, fun and recreation
- **M** Medical: Medical procedure or administration of medication
- **N** Nod, Land of: Sleeping, dozing
- **O** Objects: Displaying attachment to or relating to inanimate objects
- **P** Physical care: Receiving practical, physical or personal care
- **R** Religion: Engaging in a religious activity
- **S** Sex: Engaging in sexual expression
- **T** Timalation: Direct engagement of the senses
- **U** Unresponded to: Attempting to communicate but not receiving a response
- **V** Vocational: Engaging in work or work-like activity
- **W** Withstanding: Repetitive self-stimulation
- **X** X-cretion: Episodes related to excretion
- **Y** Yourself: Talking to oneself, or an imaginary person
- **Z** Zero option: Fits none of existing categories

*Additionally and alongside the BCC code, a p was recorded where the curtains were closed and t was recorded where the activity was therapeutic in nature.*
Summary

- The behaviour engaged in for the largest part of the time mapped by the group as a whole was sleeping or dozing (N) which comprised 23.5% of the time spent. This clearly reflects the nature of the ward, given it is an acute hospital setting, where patients are admitted as part of recovery for moderate to severe neurological conditions and thus Neurorehabilitation.
- Patients spent 16% of their day engaged in leisure (L), such as watching television, playing cards or reading. This often coincided with significant positive mood or engagement.
- 11.7% of the total time was spent engaged in talking to others (A), including staff and visitors.
- Overall, on average patients spent 9% of their time in a passive state (B), watching what was going on around them and 7% of their time in a withdrawn state which is associated with negative mood/engagement.
- Physical and medical care is an important aspect on the ward, especially given the acute nature of the setting. As such, 6.3% of the total time was spent by patients receiving practical, physical or personal care (P), which was most often carried out behind curtains. In addition 9.9% of the time was spent engaged in medical care such as being taking medication.
- 14% of the patient’s time was spent engaged in activities such as self care (D), eating or drinking (F), work or work-like activities (V), direct engagement of the senses (T),), activity prioritising intellectual abilities (I) or engaging in a form of exercise (J).

General points

- It was noticeable that when patients were occupied in any activities (e.g. self care, receiving care, eating, leisure etc) they were more engaged and/or in greater positive mood. Patients given less opportunity to engage in these types of activities, or those whom due to cognitive impairment could not initiate engagement in activities themselves, were more likely to be in negative mood states.

- There were periods of time where the bays were noticeably quieter, with less staff presence, and thus patients were less likely to have their needs identified and met, and this was reflected in higher incidences of negative mood state at these times.
Meeting the psychological needs of patients on Ward—...

In accordance with Kitwood’s book *Dementia Reconsidered*, five major psychological needs were identified (see below). These needs are often in danger of not being met in formal care settings. We witnessed many of these needs being met on and a few occasions when they were undermined.

**Comfort** – this is the provision of warmth and closeness to others, includes soothing and tenderness. People with cognitive difficulties are often in danger of being cut off from this.

**Identity** – to know who you are both in how you feel about yourself and how you think. Often, as the patient may have difficulties with memory and language, identity is often provided by those around the patient.

**Attachment** – human beings are a highly social species and need to feel attached to others particularly at times of heightened anxiety and change. Actions promoting bonding, nurturing and trust.

**Occupation** – being involved in the process of life. It fulfils a deep need that individuals can have an impact on the world and those around them. This includes empowerment, assessing levels of support required and providing it, enabling and collaboration with patients.

**Inclusion** – being part of a group is important for the survival of the human species. People with cognitive difficulties may be at great risk of being socially isolated even when they live in a communal setting. This covers including the person, fun, banishment and stigmatisation.

**Personal Enhancers and Personal Detractors:**

Person enhancers and detractors refer to interactions between a staff member and a patient that either increases or detracts from well being. They help to capture quality of person centred care upon the ward. They are divided into five categories which reflects which psychological need the interaction is meeting:
Total number of Personal Enhancers and Detractors observed over the maps.

<table>
<thead>
<tr>
<th>Psychological need</th>
<th>Highly detracting</th>
<th>Detracting</th>
<th>Enhancing</th>
<th>Highly enhancing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort</td>
<td>1</td>
<td>19</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Identity</td>
<td>1</td>
<td>8</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Attachment</td>
<td>5</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>6</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inclusion</td>
<td>4</td>
<td>8</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TOTAL NUMBER OF WARD DETRACTING EVENTS</th>
<th>TOTAL NUMBER OF WARD ENHANCING EVENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td>49</td>
</tr>
</tbody>
</table>

Summary of Personal Enhancers and Detractors

Please see the appendix for full details on the nature of all personal enhancers and detractors observed.

- The majority of staff interactions that impacted on person centred care and well-being were positive 74%.

- The majority of personal enhancers were in Comfort; reflecting strengths of the ward in providing rehabilitation, physical care and activities in a warm and comforting manner.

- Most personal detractors were in Attachment, Occupation and Inclusion suggesting patients, on occasion, felt excluded from their care or what was going on around them.

Staff strengths demonstrated in Personal Enhancers

- Small exchanges of saying “hello”, asking if patients were ok, general chat, were very important to patient well-being. One example of this was talking about a person’s belongings with them whilst cleaning the bay.

- Staff had extremely good relationships with patients who have good communication skills and were lively in character. Use of banter and humour was particularly effective and used frequently with patients who responded to this.

- Staff showed empathy and warmth towards patients, in one instance a staff member hugged a patient who had successfully had blood taken. This had a noticeable effect on the patient’s mood.
• Staff showed good use of language, relaxed pace, collaboration and respect for the patient when discussing care and rehabilitation. It was clear that patients appreciated this and benefited from it.

• There was excellent person centred care with good verbal explanations from staff to help patient understanding, from explaining personal care procedure to explaining why a staff member was busy and couldn’t help at the moment.

• Interactions were very respectful, and maintained dignity, for example staff regularly asked permission to enter curtained areas. Also it was observed that a staff member waited to serve lunch to a patient until they had finished their phone call.

• Staff were generally responsive to patients’ needs. Alarms and requests were responded to and staff frequently showed skill in identifying needs of patients.

• Staff were very good at judging the level of support a patient required and promoting independence where possible. For example adapting the service of tea-coffee for different patients while promoting their choice.

• Rehabilitation activities offered an important source of stimulation and activity for patients. Patients generally engaged very well with this.

• Staff and patients were very engaged in a Halloween party and resulted in a very large improvement in staff and patient mood that extended beyond the event itself

**Personal Detractors and issues for the ward to consider**

• There was excellent communication and banter with the more able patients, but some of the quieter patients receive less interaction from staff and therefore there were less person enhancers for these patients. On one occasion this led to a patient becoming incontinent because they were reluctant to be persistent with staff to get their attention and staff members missed those opportunities to help.

• There were some instances where staff could be more mindful of their language. For example, talking in front of patients about who is “doing” who. This was particularly noticeable during staff handover.

• At times patients had to wait for personal care, in one instance one patient waited 1 ½ hours to have a wash and this was associated with a prolonged period of negative mood.

• Several times staff approached a patient’s bed, read or removed notes, and left without interacting with the patient, with no explanation or asking their permission.

• There were some instances where aspects of care were completed without a proper explanation to the patient, reducing understanding and inclusion. For example one staff member asked another staff member about a patient in-front of them.

• When activities or stimulation were promoted by staff, it was done very skilfully. However, there was little non-rehab activity facilitated by staff.
• A lot of interaction and stimulation was provided whilst staff support a patient’s physical care. Therefore stimulation from staff reduced in the time when personal/medical care was not being performed.

• There was a reliance on patients to occupy themselves. Some patients with cognitive impairment struggled to initiate activity and staff suggesting an activity was not observed.

Things to Consider

• How do staff fill downtime in quiet periods of the shift?
• How do we interact with less able patients?
• How do we ensure that patients are involved in their own care?
Dementia Care Mapping Recap:
Aim is to observe the bays, documenting mood and engagement, and examples of care that enhances or detracts from the patient’s mood. This is observed from the perspective of the patient who may not be able to express their needs. Feedback is then given to staff with the aim of helping them to improve the person-centered care they provide.

Summary
• Staff interactions with patients were respectful and warm that enhanced their mood.
• Little interaction was observed outside formal care procedures, quiet times were linked with lower mood for patients.
• More able patients received more person-centered care in the form of banter, humour and having their needs met more readily.
• Involving patients in their care vastly improved their mood and engagement and could be done more on the ward.

Things to Consider:
• How can we fill downtime during quiet periods on shift?
• How do we interact with patients who are less able?
• How can we ensure that patients are more involved in their care?

• Being observed can be unsettling so thank you for your participation in this research project.

• We will produce a written report for the ward which will have more data in it, in addition to this summary sheet. You can access this in the reception area.

If you have any questions about Dementia Care Mapping, the research study or the observations detailed in this leaflet please contact:

Katie O’Hanlon:  katie.ohanlon@postgrad.manchester.ac.uk
Andrew Leigh:  andrew.leigh@postgrad.manchester.ac.uk
<table>
<thead>
<tr>
<th>Physical and Medical Care Provision</th>
<th>Activity/ Stimulation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Examples of person centered care:</strong></td>
<td><strong>Examples of person centered care:</strong></td>
</tr>
<tr>
<td>Giving clear explanations or instructions whilst carrying out personal or medical care involved patients more and raised their mood</td>
<td>Extremely good relationships with patients who have good communication skills and were lively in character were linked with large improvement in those patients’ mood</td>
</tr>
<tr>
<td>Staff often very respectful, such as asking permission to enter curtained areas</td>
<td>Use of humour and banter had a very positive effect of patient’s mood and engagement</td>
</tr>
<tr>
<td>Discussions with patients about how they can input into their care provision, such as deciding with them what rehab activities they would be doing, e.g. asking permission.</td>
<td>Staff members offering activities and more importantly facilitating activities, was associated with patients feeling happier and more included</td>
</tr>
<tr>
<td>Staff members approaching a patient and talking through their chart with them, this helped to include the patient in their care.</td>
<td>Rehabilitation activities offered an important source of stimulation and activity for patients. Patients generally engaged very well with this.</td>
</tr>
<tr>
<td>Staff were very good at judging the level of support a patient required and promoting independence which was often done in a way which raised the patient’s mood</td>
<td>Staff and patients were very engaged in a party and resulted in a very large improvement in staff and patient mood that extended beyond the event itself</td>
</tr>
</tbody>
</table>

**Things that could be improved:**

- Several times staff approached a patient’s bed, read or removed notes, and left without interacting with the patient, with no explanation or asking their permission.
- Talking about a patient while the patient themselves is present was observed to lower patient mood.
- At times patients had to wait for personal care, in one instance one patient waited 1 ½ hours to have a wash, having a detrimental effect on patient mood.
- On occasion personal care was completed with minimal or no communication with the patient.

**Things that could be improved:**

- When activities were suggested by staff, it was done very well. However, staff rarely facilitate non-formal care activities.
- The afternoons, between lunch and handover, on the ward are very quiet as staff tended to enter the bays less frequently which corresponded to lower patient mood.
- A lot of interaction and stimulation was provided whilst staff support a patient’s physical care and these activities often resulted in high patient enjoyment.
- There was a reliance on patients to occupy themselves. Some patients struggle to initiate activity and staff suggesting an activity for them was not observed.
# Appendix 10: List of Behaviour Category Codes from DCM-NR

## Behaviour Category Coding

<table>
<thead>
<tr>
<th>Code</th>
<th>Memory cue</th>
<th>General description of category</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Articulation</td>
<td>Interacting with others verbally or otherwise - with no obvious accompanying activity</td>
</tr>
<tr>
<td>B</td>
<td>Borderline</td>
<td>Being engaged but passively (watching)</td>
</tr>
<tr>
<td>C</td>
<td>Cool</td>
<td>Being disengaged, withdrawn</td>
</tr>
<tr>
<td>D</td>
<td>Doing for self</td>
<td>Self care</td>
</tr>
<tr>
<td>E</td>
<td>Expressive</td>
<td>Expressive or creative activities</td>
</tr>
<tr>
<td>F</td>
<td>Food</td>
<td>Eating or drinking</td>
</tr>
<tr>
<td>G</td>
<td>Going back</td>
<td>Reminiscence, reflection, life review and engaging with one’s past life</td>
</tr>
<tr>
<td>I</td>
<td>Intellectual</td>
<td>The use of intellectual abilities and brain functioning</td>
</tr>
<tr>
<td>J</td>
<td>Joints</td>
<td>Exercise or physical sport</td>
</tr>
<tr>
<td>K</td>
<td>Kum and go</td>
<td>Walking, standing or moving independently</td>
</tr>
<tr>
<td>L</td>
<td>Leisure</td>
<td>Leisure, fun and recreational activities</td>
</tr>
<tr>
<td>M</td>
<td>Medical</td>
<td>Medical discussions and procedures</td>
</tr>
<tr>
<td>N</td>
<td>Nod Land of</td>
<td>Sleeping, dozing or unconscious</td>
</tr>
<tr>
<td>O</td>
<td>Objects</td>
<td>Displaying attachment to or relating to inanimate objects</td>
</tr>
<tr>
<td>P</td>
<td>Physical</td>
<td>Receiving practical, physical or personal care</td>
</tr>
<tr>
<td>R</td>
<td>Religion</td>
<td>Engaging in a religious activity</td>
</tr>
<tr>
<td>S</td>
<td>Sexual expression</td>
<td>Sexual expression</td>
</tr>
<tr>
<td>T</td>
<td>Timalation</td>
<td>Direct engagement of the senses</td>
</tr>
<tr>
<td>U</td>
<td>Unresponded to</td>
<td>Attempting to communicate without receiving a response</td>
</tr>
<tr>
<td>V</td>
<td>Vocational</td>
<td>Work or work-like activity</td>
</tr>
<tr>
<td>W</td>
<td>Withstanding</td>
<td>Repetitive self-stimulation of a sustained nature</td>
</tr>
<tr>
<td>X</td>
<td>X-cretion</td>
<td>Episodes related to excretion</td>
</tr>
<tr>
<td>Y</td>
<td>Yourself</td>
<td>Interaction in the absence of any observable other</td>
</tr>
<tr>
<td>Z</td>
<td>Zero option</td>
<td>Fits none of existing categories</td>
</tr>
</tbody>
</table>
Appendix 11: Approval letter from University of Manchester Research Review Committee

Mr Andrew Leigh and Ms Katie O’Hanlon

Dear Andrew & Katie

Feedback from Research Subcommittee  19th December 2011

Thank you for your revised combined research proposal which was considered by the Research Sub-Committee Meeting on 19th December 2011. The committee does ask that Andrew’s hypothesis 1 be amended as discussed in the meeting and that you collect as much information as appropriate regarding referral routes and nature of injury so as to permit any post-hoc or covariate analysis as may be required. With regard to Katie’s research, the specific aims of the study need to be more clearly operationalised.

With these caveats, the committee were satisfied that the revisions made were appropriate and in accordance with the feedback from the meeting of 21st November 2011 and you may now proceed with your research as set out in your proposal, pending approval of the revised protocol by Dr Anja Wittkowski in her capacity as deputy chair of the Research Sub-Committee.

For the purposes of ethical scrutiny by relevant NHS and/or University bodies, this letter may be taken as confirmation that your research proposal has been independently reviewed and that it is considered to meet necessary scientific and methodological standards.

On behalf of the Research Subcommittee, we wish you good luck with your research work.

Yours sincerely

Dr Dougal Julian Hare

Research Director

Panel Chair, Research Sub-Committee
Appendix 12: Favourable Opinion Letter from NHS Ethics Committee

Health Research Authority
NHS
National Research Ethics Service

NRES Committee North West - Haydock
North West Centre for Research Ethics Committees
3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 605 7827
Facsimile: 0161 605 7299

20 July 2012

Mr Andrew Leigh
Trainee Clinical Psychologist
Manchester Mental Health and Social Care Trust
Division of Clinical Psychology
University of Manchester
2nd Floor, Zochonis Building
Oxford Road
M13 9PL

Dear Mr Leigh

Study Title: The feasibility and validity of a new adapted Dementia Care Mapping (UCM) tool in a range of Clinical Neuroscience settings, and the relationship between UCM, cognitive impairment and dependency.

IRAS project number: 98462
REC reference: 12/NW/0480

Thank you for your letter of 17 July 2012, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair (Dr Tim Sprosen - Epidemiologist).

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

A Research Ethics Committee established by the Health Research Authority
Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to
management permission being obtained from the NHS/HSC R&D office prior to the start of
the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of
the study.

Management permission or approval must be obtained from each host organisation prior to
the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations
involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated
Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential
participants to research sites ("participant identification centre"), guidance should be sought
from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the
procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied
with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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<tbody>
<tr>
<td>Covering Letter signed Katie O’Hanlon</td>
<td></td>
<td>12 June 2012</td>
</tr>
<tr>
<td>REC application 90462/332494/1222</td>
<td></td>
<td>14 June 2012</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>01 May 2012</td>
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<tr>
<td>Investigator CV Andrew Leigh</td>
<td></td>
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<tr>
<td>Investigator CV Katie O’Hanlon</td>
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<tr>
<td>Investigator CV Dr Dougal Julian Hare</td>
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<tr>
<td>Investigator CV Dr Russell Sheldrick</td>
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<tr>
<td>Participant Consent Form: Staff</td>
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<tr>
<td>Information Sheet: GP/Health Professional</td>
<td>1</td>
<td>01 April 2012</td>
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<tr>
<td>Questionnaire: The Barthel Index</td>
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<tr>
<td>Questionnaire: Addenbrooke’s Cognitive Examination – ACE-R</td>
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A Research Ethics Committee established by the Health Research Authority
<table>
<thead>
<tr>
<th>Questionnaire: Client-Centred Rehabilitation Questionnaire</th>
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<tbody>
<tr>
<td>Questionnaire: Northwick Park Dependency Scale</td>
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<tr>
<td>Evidence of insurance or indemnity signed Lynne MacRae</td>
<td>25 May 2012</td>
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<td>Letter from Sponsor signed Lynne MacRae</td>
<td>25 May 2012</td>
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<tr>
<td>Letter from Statistician: Large Scale Research Project</td>
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<td>Proposal Submission Proforma</td>
<td>31 October 2011</td>
</tr>
<tr>
<td>Feedback from Research Subcommittee</td>
<td>12 December 2011</td>
</tr>
<tr>
<td>Response to Request for Further Information from Mr Andrew Leigh</td>
<td>17 July 2012</td>
</tr>
<tr>
<td>Participant Information Sheet: Patients</td>
<td>2 July 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Patients</td>
<td></td>
</tr>
<tr>
<td>Participant Information Sheet: Consultees</td>
<td>2 July 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Consultee Declaration Form</td>
<td></td>
</tr>
<tr>
<td>Participant Information Sheet: Staff</td>
<td>2 July 2012</td>
</tr>
<tr>
<td>Participant Information Sheet: Visitors</td>
<td>2 July 2012</td>
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**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

**Reporting requirements**

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

**Feedback**

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NW/0480 Please quote this number on all correspondence

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A Research Ethics Committee established by the Health Research Authority
With the Committee’s best wishes for the success of this project

Yours sincerely

[Signature]

On behalf of:

Professor Ravi S Gulati
Chair

Email: noel.graham@northwest.nhs.uk

Enclosures: “After ethical review – guidance for researchers”

Copy to: Ms Lynne MacRae
FMHS Research Office
3.53 Simon Building
University of Manchester
Oxford Road
M13 9PL

Rachel Georgiou
Salford Royal Foundation Trust
Research and Development
Ground Floor
Summerfield House
Stott Lane
Salford M6 8HD

A Research Ethics Committee established by the Health Research Authority
Appendix 13: Approval Letter from NHS Research and Development

NHS Salford+D Director: Professor Bill Ollier
NHS Salford+D Associate Director: Rachel Georgiou
NHS Salford+D Manager: Sue Gowland
Salford+D web address: http://www.nhssalfordrd.org.uk/
ReGrouP web address: http://www.gmregroup.nhs.uk/index.html

23rd July 2012

Mr Andrew Leigh
Trainee Clinical Psychologist
Manchester Mental Health and Social Care Trust
Division of Clinical Psychology
University of Manchester
2nd Floor, Zochonis Building
Oxford Road
M13 9PL

Dear Mr Leigh

Study Title: The feasibility and adaptability of a new Dementia Care Mapping Tool (DCM) in a range of clinical Neuroscience settings and the relationship between DCM cognitive impairment and dependency

REC Reference: 12/NW/0480
EuDraCT Reference: N/A
R&D Reference: 2012/144NEURO

Thank you for forwarding all the required documentation for your study as above. I am pleased to inform you that your study has been registered with NHS Salford+D and has gained NHS R&D approval from the following NHS Trust:

- Salford Royal NHS Foundation Trust


It is a legal requirement for Principal Investigators involved in Clinical Trials to have completed accredited ICH GCP training within the last 2 years. Please ensure that you provide the R&D Department with evidence of this (certificate for completing the course). A list of GCP training courses can be obtained from the R&D Office.

All researchers who do not hold a substantive contract with the Trust must hold an honorary research contract before commencing any study activities related to this approval. The ‘Research Passport Application Form’. This can be obtained from web addresses: http://www.gmregroup.nhs.uk/researchers/passports.html and http://www.hope-academic.org.uk/academic/salfordrd/Research%20Passports.html. This form should be completed and returned, with a summary CV and recent (within 6 months) CRB to the address shown above.

Research & Development Department
Ground Floor, Summerfield House,
544 Ecosse New Road, Salford M60 6AP

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It is a condition of both NRES and NHS R&D approval that participant recruitment data should be forwarded on a regular basis. Therefore, progress reports must be submitted annually to the main REC and copied to the R&D office until the end of the study.
http://www.nres.npsa.nhs.uk/applications/after-ethical-review/annual-progress-reports/

Where clinical trials of investigational medicinal products are sponsored by Salford Royal NHS Foundation Trust or Salford Primary Care Trust, it is a condition of Trust approval that Chief Investigators submit quarterly progress reports (to include Annual Safety Reports at the appropriate time) to R&D. For clinical trials of investigational medicinal products hosted within Salford Royal NHS Foundation Trust and Salford Primary Care Trust, the local PI will be expected to submit bi-annual progress reports to R&D. It is also a condition of approval that delegated duties (as agreed within clinical trial agreements and trial delegation logs) are fulfilled by only those delegated to undertake a specific duty. This will be monitored by the Sponsor’s Representative during routine monitoring of the trial. Persistent non-compliance with these requirements may result in removal of Sponsorship or Trust R&D Approval.

Any amendments to the study should also be notified and approval sought by Ethics Committee and R&D Department. Where Salford Royal NHS Foundation Trust or Salford Primary Care Trust is acting as Sponsor then amendments or changes MUST be discussed with the Sponsor prior to REC submission. On completion of the study you are required to submit a ‘Declaration of End of Study’ form to the main REC, which should also be copied and forwarded to the R&D office at the address shown above.

Any serious adverse events or governance issues related to the research must be notified to the R&D office.

Yours sincerely,

Sue Gowland
NHS Salford R+D Manager