Care Mapping in Clinical Neuroscience Settings: Cognitive Impairment and Dependency

Andrew James Leigh[a], Katie O'Hanlon[b], Russell Sheldrick[c], Claire Surr[d] & Dougal Julian Hare[e]

[a] St George Healthcare Group, St Mary's Hospital, Warrington, UK
[b] West London Mental Health NHS Trust, London UK
[c] Department of Neuropsychology, Salford Royal Foundation Trust, Hope Hospital, Salford, UK
[d] Division of Dementia Studies, School of Health Studies, University of Bradford, Bradford, UK
[e] School of Psychological Sciences, University of Manchester, Manchester, UK

Abstract

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. 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 Dementia Care Mapping – Neurorehabilitation (DCM-NR) and categorised based on severity of cognitive impairment.

A significant difference in the behaviours participants engaged in, their wellbeing 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–illbeing scores and 17.2% of the variance in potential for positive engagement.

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 providing insights into patient experience

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 (PCC) has many definitions and indeed a range of synonymous terms such as individualised care and patient-centred care. The common theme across the many 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 UK (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 (NICE, 2008), head injury (NICE, 2007) as well as dementia (NICE, 2006).

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 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 (Brooker, 2005; Fossey, Lee & Ballard, 2002).

DCM is also a process to promote and improve the level of PCC in health and social care settings. 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 effect DCM has on the well-being of patients (Brooker, 2005; Brooker, Foster, Banner, Payne, & Jackson, 1998). 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, Dijkstra, Tuinstra, & Groothoff, 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 can improve 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 client groups. DCM has been implemented in learning disability residential services (Persaud & Jaycock, 2001) and hospital wards for patients with a variety of physical health problems (Woolley, Young, Green & Brooker, 2008). Despite DCM not being designed for use in these settings or with these patient groups, researchers 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, McIntosh, Sheldrick, Surr & Hare, 2013). Utilising Q-methodology alongside DCM in a neurorehabilitation ward it was concluded that DCM was feasible and acceptable for 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 devised: Care Mapping – Neurorehabilitation (DCM-NR: Bradford Dementia Group, 2012).

Patients in clinical neuroscience 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 their quality of life (Vickery, Gontkovsky & Caroselli, 2005; Andelic et al. 2009) and often require long-term care and rehabilitation.

It is 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 Carbonell, Pinto & Sepulveda. 2004). Some DCM research has looked at the effect of cognitive impairment on person-centered care and well-being, albeit in people with dementia. Much of this evidence is unclear 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 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, Folstein & McHugh, 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 et al.' 2005) with researchers and governments alike recognising that traumatic brain injury is a predominant cause of disability, particularly in those under the age of 35 years (Seel et al., 2003). Unemployment following TBI ranges from 10 to 70% (McCrimmon & Oddy, 2006) and those that 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 et al., 2005), with those who have less functional ability being more likely to develop a psychological condition, such as depression or anxiety (Schonberger, Ponsford, Gould, & Johnston, 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-ill-being scores (Edelman, et al., 2004) . Brooker et al. (1998) linked this relationship to a mediating factor of poorer care for those with higher dependency, finding that with three cycles of DCM the relationship of lower well-being for those with 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 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.

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:

Hypothesis 1: A negative relationship between dependency and the patient's observed mood/engagement and potential for positive engagement (PPE). (1a) Greater mood and engagement (DCM: WIB scores) will be observed in those patients with less dependency, as measured by the Northwick Park Dependency Scale. (2b) Higher PPE score (DCM) will be observed in those patients with less dependency (NPDS).

Hypothesis 2: A negative relationship between cognitive impairment and the patient's observed mood/engagement and PPE. (2a) Greater mood and engagement (DCM: WIB scores) will be observed in those patients with less cognitive impairment. (2b) Higher PPE score (DCM) will be observed in those patients with less cognitive impairment.

Hypothesis 3: 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 were recruited from six clinical neuroscience wards at Salford Royal NHS Foundation Trust, UK. 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 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 was recruited into the study, and observed using DCM-NR. Of these, cognitive assessment using the ACE-R was completed with 29, although severity of cognitive impairment was determined for the remainder.

Table 1. Participant Demographics (n = 65)

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Age	Mean (SD)	57.34 (18.24) years
	Range	18 – 93 years
Gender	Male	18 (27.7%)
	Female	47 (72.3%)
Ethnicity	White British	54 (83.1%)
	Black British	5 (7.7%)
	Asian British	2 (3.1%)
	Other	4 (6.2%)
Time Since Admission (days)	Median (SD)	22 (61.02) days
	Range	0 – 328 days
Cause of admission	Traumatic Brain Injury	11 (16.9%)
	Cerebrovascular	20 (30.8%)
	Spinal Cord Injury	11 (16.9%)
	Tumour	5 (7.7%)
	Other Neurological conditions	18 (27.7%)
Northwick Park Dependency Scale (NPDS)	Mean (SD)	28.03 (19.75)
	Range	0 - 72
Severity of Cognitive Impairment	None	29 (44.6%)
	Mild	10 (15.4%)
	Moderate	14 (21.5%)
	Severe	11 (16.9%)

Measures

Dementia 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 its feasibility and acceptability on a neurorehabilitation ward was initially established by McIntosh et al. (2012) and Westbrook, McIntosh, Sheldrick, Surr, and Hare (2013). A further study (O'Hanlon, in preparation) has examined its feasibility for use on a broad range of neuroscience wards.

Participants in a communal area, such as a ward bay, are observed for a length of time (2 ½ hours in this study). At three-minute intervals two recordings were 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 (-5, -3, -1, +1, +3 and +5) (ME 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. Staff interactions with patients that enhance their well-being are recorded as personal enhancers (PEs) and interactions diminishing their well-being are recorded as personal detractors (PDs). PEs and PDs are categorised on Kitwood's (1997) psychological needs: attachment, comfort, inclusion, occupation, and identity.

Adaptions to the DCM 8 to create the first version of a tool suitable for testing in neurorehabilitation settings (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, Edelman, and Kuhn (2006) expanded upon this and found that shorter mapping periods were feasible. Therefore it was decided to employ a 2 ½ 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) (Turner-Stokes et al. 1998). This is a widely used, reliable and valid measure of dependency (Siegert & Turner-Stokes, 2010) that is already routinely completed in all the clinical neuroscience settings included in this study. It was completed by the member of staff most able to complete it, 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 ere weighed against the impact on the participants

completing such an assessment. Consideration was also given to the potential difficulties in completing a battery of neuropsychological measures in an acute hospital setting. A more in-depth neuropsychological assessment would have provided more detailed information but a large proportion of potential participants may have been unable to complete the assessment and thus would have been excluded from the research. A brief screening measure would enable an assessment and judgement of 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: Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006) was chosen due to its prior validation in neuroscience settings (Gaber, 2008) and its ability to detect mild cognitive impairment (Crawford, Whitnall, Robsertson, & Evans, 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 judgement by an experienced clinician and the ACE-R as a standard 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 as having 'severe cognitive impairment'. 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 75 were categorised into the 'moderate cognitive impairment' group; and 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

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 about the research project by an experienced clinician. Formal consent was sought from both staff members and patients at least 24 hours before mapping was due to be undertaken. At the same time, the clinician also assessed capacity and sought assent in those cases where the patient was deemed to lack capacity.

Mapping was conducted as per the DCM-NR manual (Bradford Dementia Group, 2012) by two researchers (AL and KOH) 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. 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. 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 which 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.

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 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 Mean PPE was 62.75% (SD = 28.18%) with a range of 2-100%. A significantly positive correlation, using Spearman's Rho, between WIB scores and PPE was detected at the .01 level (two tailed) (r_s=.620, n=66, p=.001).

Personal enhancers (PEs) and personal detractors (PDs) per individual were not recorded because there was little staff-patient interaction. Overall, there were more PEs (76%) than PDs (24%). Many PEs were meeting the patients' needs for

comfort, but examples of staff-patient interaction were found for all five psychological needs of attachment, identity, occupation, inclusion and the aforementioned comfort. PDs, although less numerous, were more evenly spread among the five psychological needs. For a more thorough description of the DCM-NR data, its acceptability and psychometric properties see O'Halnlon et al. (In preparation).

Kolmogorov-Smirnov tests of normality were completed for participant scores on the NPDS, and their WIB scores and their PPE scores. WIB scores (0.099, p = .192) and NPDS scores (0.105, p = .074) were considered to be normally distributed (.05 significance level). PPE, however, was not normally distributed at a .05 significance level (0.133, p = .006).

Results

Sixty seven participants either gave consent, or a nominated person gave advice on their best wishes, and were 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.

Hypothesis 1: Analysis of dependency and DCM

To test Hypothesis 1a, a Pearson's correlation was conducted between NPDS and WIB scores, with a significant negative correlation detected (r = -.447, n = 64, p <.001).

To test Hypothesis 1b, a Spearman's Rho correlation was performed between PPE and NPDS scores, with a significant negative correlation detected (r_s = -.376, n = 64, p = .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 WIB scores. There was a significant

effect of cognitive impairment on WIB scores at the p < .05 level for the four categories F(3, 60) = 9.910, p <.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 .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) or 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.

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<.05 level for the four categories F (3, 60) = 5.20, p=.003) was found. Post hoc comparisons revealed a significant difference between the severe categories of cognitive
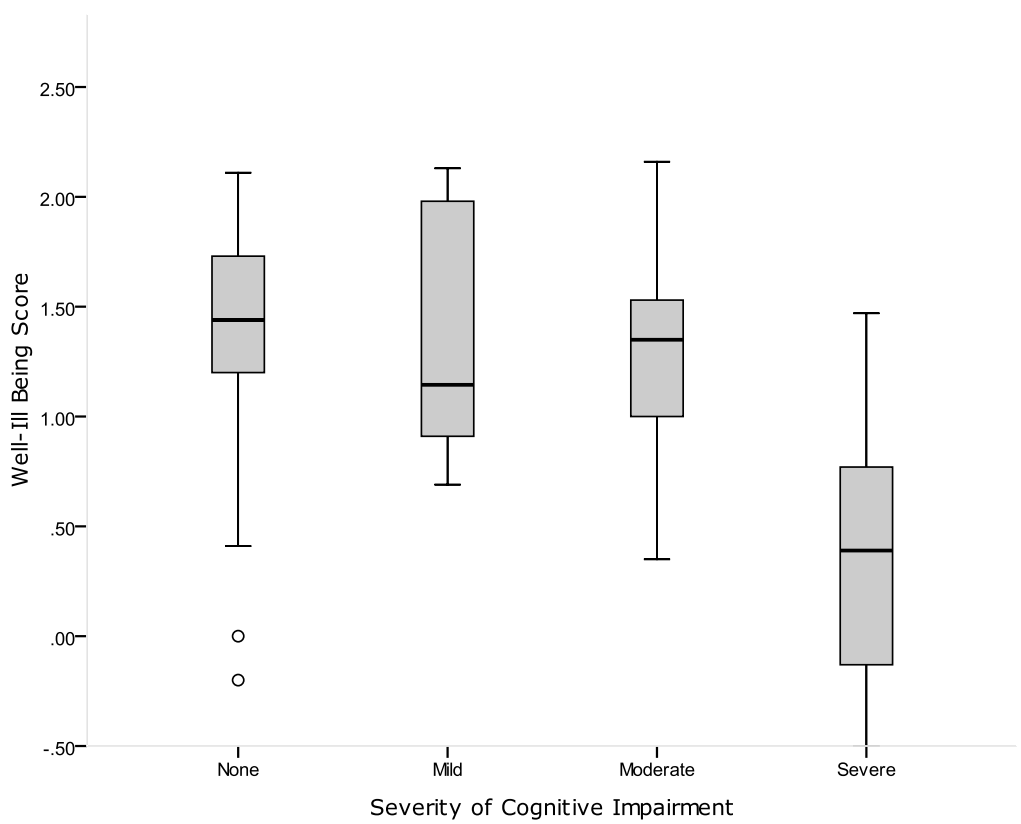

Figure.1 Boxplot showing WIB scores for categories of cognitive impairment.

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 $p > .05$ level for the four categories $F_{(3, 59)} = 7.533$, $p < .001$). 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.

Cognitive impairment and NPDS scores, significantly predicted WIB scores and 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 $F_{(2, 60)} = 10.75$, $p < .001$, which accounted for approximately 23.9% of the variance in WIB scores (adjusted $R^2 = .239$) with significant predictor variables, at the .05 level, of Cognitive Impairment ($\beta = -0.291$, p=.026) and Dependency (β=-0.303, p=.021). Multiple regression analysis was 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 $R^2 = 0.172$, $F_{(2,60)} = 7.45$, P<.001). Cognitive impairment (β=-0.277, p=.042) predicted PPE alone; however, dependency ($\beta = -0.239$, p=.077) did not predict PPE alone.

Discussion

The results of this 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 that those patients with greater dependency were observed to have lower well-being using Dementia Care Mapping (Edelman, et al 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 et al. (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 regard 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, et al 2005). The interaction of these two factors in influencing well-being is less clear and the present data demonstrate 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 wellbeing, thus highlighting the need for systemic intervention in these settings. DCM-NR may meet this need since 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).

Personal enhancers (PEs) and detractors (PDs) were not recorded for individual patients which prevented a direct comparison between staff–patient interaction and the level of dependency or cognitive impairment of the patient. However, it was noted that those patients with lowest levels of cognitive impairment and dependency, and importantly able to reciprocate positive interactions from staff, for

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example by laughing, were in receipt of more positive interactions and thus PEs. This would result in further improving the well-being of those patients who were either already in a high well-being state or had the potential to be in a high well-being state. Patients engaged in a positive activity had more opportunity for staff–patient interaction that those patients withdrawn or in pain. However, positive staff–patient interactions were noted with those patients in distress/pain, possibly resulting in the high number of interactions providing comfort to the patient. Improvements in staff–patient interactions with those patients at most need of such could likely be achieved through repeated rounds of DCM-NR as part of a systemic intervention on improving person-centred care.

The adaptations made to DCM to producing 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-ill 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 appear to detract from the ability to measure person centred care in this study.

The strengths of this study lie in the range of neuroscience settings used, allowing for generalisations to be made more confidently. DCM-NR had previously only 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 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 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 were 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. 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 et al., 2006) for health and social care dementia settings. However, 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 et al. (2006) may not apply to acute hospital settings and further research is needed to establish periods of the day representative of the day as a whole; this would be inherently difficult due to varying ward timetables, 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, its use in this study was problematic. Firstly, the measurement 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, from 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 previously 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.

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 wellbeing the most and how rehabilitation can target these domains. A study employing DCM (Potkins et al., 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 has 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 (Stevens et al., in progress; McIntosh et al., 2012) and the feasibility further established in a range of neurorehabilitation settings (O'Hanlon, in preparation), 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.

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 have patients who would benefit 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).

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.

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