

## Factors influencing community case management and care hours for clients with traumatic brain injury living in the UK

Article (Published Version)

Clark-Wilson, Jo, Giles, Gordon Muir, Seymour, Stephanie, Tasker, Ross, Baxter, Doreen M and Holloway, Mark (2016) Factors influencing community case management and care hours for clients with traumatic brain injury living in the UK. *Brain Injury*, 30 (7). pp. 872-882. ISSN 0269-9052

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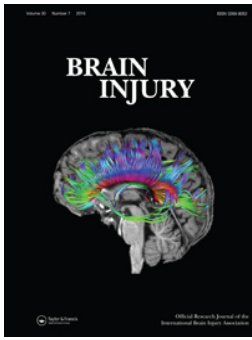
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To cite this article: Jo Clark-Wilson, Gordon Muir Giles, Stephanie Seymour, Ross Tasker, Doreen M. Baxter & Mark Holloway (2016) Factors influencing community case management and care hours for clients with traumatic brain injury living in the UK, *Brain Injury*, 30:7, 872-882, DOI: [10.3109/02699052.2016.1146799](https://doi.org/10.3109/02699052.2016.1146799)

To link to this article: <http://dx.doi.org/10.3109/02699052.2016.1146799>



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Published online: 08 Apr 2016.



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## ORIGINAL ARTICLE

# Factors influencing community case management and care hours for clients with traumatic brain injury living in the UK

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### Abstract

**Objective:** To investigate the relationship between deficits associated with traumatic brain injury (TBI) and case management (CM) and care/support (CS) in two UK community samples.

**Research design:** Prospective descriptive study.

**Method:** Case managers across the UK and from a single UK CM service contributed client profiles to two data sets (Groups 1 and 2, respectively). Data were entered on demographics, injury severity, functional skills, functional-cognition (including executive functions), behaviour and CM and CS hours. Relationships were explored between areas of disability and service provision.

**Results:** Clients in Group 2 were more severely injured, longer post-injury and had less family support than clients in Group 1. There were few significant differences between Groups 1 and 2 on measures of Functionalskill, Functional-cognition and Behaviour disorder. Deficits in Functionalskills were associated with CS, but not CM. Deficits in measures of executive functions (impulsivity, predictability, response to direction) were related to CM, but not to CS. Insight was related to both CM and CS. Variables related to behaviour disorder were related to CM, but were less often correlated to CS.

**Conclusions:** The need for community support is related not only to Functionalskills (CS), but also to behaviour disorder, self-regulatory skills and impaired insight (CM).

### Keywords

Traumatic brain injury, brain injury, case management, care needs, neurobehavioural disability, behaviour disorder, executive function

### History

Received 20 September 2015

Revised 19 January 2016

Accepted 22 January 2016

Published online 8 April 2016

### Introduction

Successful community living is the ultimate aim of rehabilitation after TBI, but people with TBI are generally less integrated into the community than those without TBI [1,2] and may require ongoing support to maintain community living. There has been little research to examine the relationship between impairment and disability and the need for ongoing support in persons with TBI living in the community [1,3,4]. This paper explores the relationships between TBI-related impairments and disabilities and the use of case management (CM) and care/support (CS) hours, in two samples of clients supported in the UK by independent CM companies.

Prediction of long-term care costs is economically important for funding agencies. Life expectancy after TBI is estimated to be reduced by only 3–7 years [5–7], so young people with TBI can

expect to live for decades following the injury. In the context of litigation claims, the prediction of care costs has to occur by the time of the legal settlement and relatively soon after injury (often in a 3–5 year window). For clients with severe impairments, CM and CS may be required lifelong. Long-term estimates for CM and CS need to account for the nature of the client's injury, the associated functional deficits, likely progress in rehabilitation and environmental factors that may ameliorate or exacerbate disability and community participation [8].

A number of researchers have estimated the costs of TBI inpatient hospitalization and the projected cost-savings in lifelong community care costs that could result from acute and post-acute rehabilitation [9–11]. Turner-Stokes et al. [9] reported the greatest savings were for patients with TBI who had the highest dependency. Projected community costs took into account staff time in the various disciplines, as these accounted for most care costs in inpatient rehabilitation settings [12,13]. It should be noted that time estimates were made based on care or treatment requirements related to basic ADL and mobility deficits and risks associated with behaviour disorders. The estimates did not consider a range of cognitive and lifestyle factors that may be relevant to community care costs or quality-of-life.

Wood et al. [10] estimated lifetime care cost-savings that might be achieved from intensive, post-acute social and behavioural rehabilitation aimed at increasing community integration. These

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authors estimated that notional lifetime cost-savings in the most severely impaired persons could be in excess of one million pounds (1.5 million dollars) [10]. A study by Worthington et al. [11] confirmed this level of saving as a result of post-acute rehabilitation for persons admitted to rehabilitation within 12 months of injury. They also found lower, but still significant cost-savings, for those admitted more than 12 months after injury [11]. Projected cost-savings were related to reduced intensity of service in terms of place of residence, amount and type of care, functional independence, constructive occupation and performance of social roles [11].

The most rapid period of improvement for most persons with TBI occurs in the first 1–2 years, but it is now recognized that improvements in function can occur many years post-TBI [14–16]. Although those who present with significant deficits 3–5 years post-injury are more likely to require long-term CM or CS, improvement continues to be possible [15,16]. When physical or cognitive impairments are severe, prediction of CM and CS needs may be relatively straightforward. However, ‘invisible’ deficits, such as lack of insight, executive function deficits or behaviour disorders, may be overlooked entirely. These omissions could partly explain why injury severity *per se* and functional status at discharge from rehabilitation account for so little of the variance when predicting outcome [15,16]. Hoofien et al. [17] examined 76 persons with severe TBI 10–20 years post-injury. Psychiatric symptomatology and family and social functioning were markedly affected, whereas cognitive, vocational and independent functioning were somewhat less so. High rates of depression, loneliness and family members’ sense of burden were found. Hoofien et al. [17] concluded that, even after a decade post-injury, professional assistance may be needed to maintain a reasonable psychosocial quality-of-life for persons with TBI and their families. Understanding lack of insight, executive functioning and mood regulation are critical for estimating the need for services and evaluating risk in a community setting. Martzke et al. [18] found that, in their sample of clients with anosmia secondary to TBI (i.e. indicative of orbital-frontal dysfunction), at least half would have been misdiagnosed as having no neuropsychological impairment, in the absence of collateral interviews. It is essential to have detailed and specific information about an individual’s level of functioning in real life at the time when clients relocate into community settings, if the person’s needs are to be met and appropriate support provided [19].

Lack of insight is frequently reported as a consequence of TBI [20]. Evidence is contradictory regarding whether lack of insight is associated with severity of injury, as measured by the score on the Glasgow Coma Scale (GCS) [21] or duration of post-traumatic amnesia (PTA) [22,23], with specific cognitive deficits or with general intellectual functioning [20]. Lack of insight is associated with increased occurrence of behavioural disturbance [20], poorer functional recovery and rehabilitation outcome [23,24], worse employment outcomes [25] and poorer spousal relationships [26]. In the context of inadequate caregiver support, lack of insight is associated with increased caregiver burden [22].

The term executive function (EF) represents a cluster of abilities fundamental to self-determination and engagement in meaningful activities [27–30]. EF is responsible for a person’s ability to establish and meet complex self-directed goals [31,32] and is

intimately linked to insight and self-regulation [33,34]. Individuals with EF deficits experience functional problems, including vocational disability [35,36], interpersonal skills deficits [37] and a decline in occupational performance and community participation [36,38,39]. Office-based neuropsychological measures, taken in isolation, often fail to capture EF deficits [40] and are recognized as poor predictors of a person’s ability to manage in everyday life [41,42]. Probably the best indicator of EF deficits is direct observation of the individual’s actual performance *in situ*, by persons who know the client well [42].

Verbal and physical aggression are known to be common following TBI [3,43,44], but rates of aggression have been difficult to establish. Published prevalence estimates of rates of aggression after TBI frequently have different sampling methods, small sample sizes and use differing definitions of aggression and data collection periods [3,45–47]. During 1 month of observation, 5 years post-injury, Baguley et al. [46] found 51% of persons with TBI were verbally aggressive and 19% were physical aggressive. Baguley et al. found depression predicted aggressive behaviour, but severity of injury did not. During 3 months of observation, Sabaz et al. [48] reported an incidence of verbal aggression of 27.2% and of physical aggression of 10.3% in their predominantly post-acute TBI population (75.3% > 12 months). However, when only persons with a PTA in excess of 6 months were considered, the incidence of verbal aggression was 45.9% and physical aggression was 27%. Time post-injury may be an important factor, and in Brooks et al.’s [43] sample of individuals who had a very severe brain injury, threats and gestures of violence increased from 15% to 54% from 1 to 5 years post-injury, and physical violence against relatives increased from 10% to 20% close to the rates reported by Baguley et al. [46]. Higher rates of verbal and physical aggression have been reported in the literature, but predominantly in acute samples which may include individuals with PTA or delirium [47–50] or in samples specifically selected for the presence of challenging behaviour [3,48,51].

Evidence is inconsistent regarding how severity or location of TBI may influence the frequency and nature of aggression. Severity of injury was unrelated to aggression in the studies by Baguley et al. [46], Rao et al. [45] and Tateno et al. [52], but both verbal and physical aggression increased in tandem with increased PTA duration in the study of Sabaz et al. [48]. Other studies have supported the relationship between frontal lobe involvement and aggression, e.g. Grafman et al. [53] and Kim [54]. In contrast, Pontius and LeMay [55] reported an association with temporal lobe involvement and aggression.

A number of studies have considered the long-term incidence of functional disabilities in individuals living in the community following a TBI [1]. In a 3–5 year follow-up study, Dikmen et al. [56] estimated that ~ 10% of persons with severe TBI in their sample required long-term assistance and were dependent on others for help with basic ADLs. There was a strong relationship between both neuropsychological and functional outcomes and severity of injury, but not with emotional functioning and quality-of-life [56].

Whitnall et al. [57] describe a large cohort of young people and adults with TBI. When assessed 5–7 years after hospital admission, 24% had died and, of the survivors, 19% were rated as severely disabled and 33% moderately disabled on

the Glasgow Outcome Scale-Extended (GOSE) [58]: 13% had some impairment in basic ADLs (Barthel Index score < 20) and 4% had marked deficits (Barthel Index score < 10) [59]. The overall rate of disability was similar for those who sustained mild and moderately-severe injuries at both 1 and 5–7 years (~ 50%). Within the group with severe injuries, the incidence of disability remained ~ 75%.

When the same sample was followed up at 12–14 years post-TBI, the proportion of individuals with severe and moderate disability on the Glasgow Outcome Scale-Extended was similar (i.e. 20% severe and 31% moderately disabled) [60]. The prospect was poor for people severely disabled at 1 year, and four out of five were severely disabled or dead at 12–14 years, even though the median age of the sample was only 40 years. In contrast, a quarter to a half of the total sample showed some late functional improvements [60]. Generalizations from this sample should be made with caution as the most common causes of injury were falls and assaults (77%) and alcohol was associated with the majority of cases (61%). In addition, a quarter of the sample had sustained a prior TBI [61].

A far higher proportion of individuals have been reported to have deficits in domestic and community skills than those with impairments in basic ADL's. Dikmen et al. [56] found that ~ 60% of individuals with moderate or severe TBI, followed up one year after inpatient rehabilitation, reported cognitive problems when performing everyday activities or life roles and, as a result, needed partial or total help. Similarly the study by Powell et al. [62] identified 43% of their sample as having reduced independence with home management activities (e.g. cooking, cleaning, shopping, laundry), with 13% being largely dependent on others.

### Case management

There are various models of case management (CM) and only a limited number of systematic studies have been undertaken regarding the application of CM models for people with TBI [63,64].

Greenwood et al. [65] conducted a prospective, controlled, unmatched non-randomized study of the effects of providing CM for 2 years after TBI, to examine the potential role of CM in bridging the transition from hospital to community. Case managers adopted an enabling rather than a therapeutic role, focusing on referring patients to outside services. Greenwood et al. [65] found no advantage in terms of outcome between the CM group and the control group, concluding that no amount of CM services would compensate for inadequate rehabilitative service provision [65].

Diwan [66] identified factors associated with CM services in a Medicaid-waver funded home-care programme in the US. As might be expected, an increase in CM usage was associated with problematic client behaviours, difficulties with informal caregivers (e.g. caregivers who were in poor health or difficult to work with) and when there were problems with formal support services (in-home services). In addition, clients with greater functional ability had higher CM service use [66].

In a more recent study, Arnold and Elder [4] documented factors influencing the allocation of CM hours to persons with TBI by an insurance-funded CM provider, based in Australia. Most clients had a severe TBI and most had a

PTA of between 2–7 days. Mean CM hours were 2.5 hours per month (ranging from 0.25–15.50 hours per month) and increased in the context of inappropriate behaviour, troubled family dynamics and problems with accommodation. A positive correlation was found between severity of injury (PTA) and the amount of CM.

In the UK, there continues to be confusion over the generic term 'case management' [67], as services differ depending on the source of funding. CM and care/support (CS) can be funded via a variety of sources including Clinical Commissioning Groups (CCG) and Social Services (SS) or from litigation claims. In statutory services (CCG and SS), there are stringent criteria to determine eligibility for a service and access to funds. These criteria may not include the full range of cognitive and behavioural deficits that may follow TBI. Additionally, service provision is dependent on the resources available and family members are often expected to provide the majority of care for their relative with TBI, irrespective of the associated burden.

In contrast, in litigation claims, the courts assume '... that the claimant should, as nearly as possible, be put in the same position as he would have been had he not sustained the injury' ([68], p. 297). An assessment of damages in this context should allow claimants sufficient financial resources to enable them to return to a lifestyle that they would have reasonably enjoyed prior to the accident.

The British Association of Brain Injury Case Managers (BABICM) defined CM as:

... a collaborative process, which assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet an individual's health and wellbeing, education and/or occupational needs, using communication and available resources to promote quality, cost effective and safe outcomes. [69]

(See the babicm web site [69] for the competency framework and standards for UK case management).

Case managers accredited by BABICM are expected to identify goals, which are shared with the client and their family and also rehabilitation professionals. They are expected to promote the systems, structures and support, which will facilitate optimal recovery and, if appropriate, to maintain the client in the community long-term. The case manager recruits support staff and facilitates suitable training, organizes relevant therapeutic services and co-ordinates, reviews and monitors such services, as required. At the core of the intervention is the personal trust and supportive relationship created between the case manager, client and relevant family members or caregivers. This trust is important for clinically-informed judgements that respect the client's needs and wishes [70].

To date, no studies have reported on clients served by this model of CM or reported on the association between hours of CM or CS and clients' impairments or abilities. The current study examines the intensity of community care, based on an exploration of CM and CS hours, in association with a comprehensive assessment of functional, cognitive and behavioural changes for clients in the post-acute stage of recovery from TBI. The study involved case managers experienced in the



field of TBI, whose funding primarily came from litigation claims rather than statutory services.

### Rationale for the current study

An unpublished pilot study in 2001 found that items in the Adaptive Behaviour and Community Competency Scale (ABCCS) relating to insight and behaviour disorders were associated with hours of CM, but not to hours of CS. Although these findings were consistent with the clinical experience of one of the authors (JCW), they were considered to be preliminary and to require testing with a larger sample.

The current study was designed to test the following hypotheses:

- (1) ABCCS items that related specifically to EF deficits, such as poor planning, impaired insight, reduced compliance with direction and impulsivity, would be correlated to hours of CM, but not to hours of CS.
- (2) ABCCS items relating to behavioural dysregulation (e.g. verbal and physical aggression, decreased frustration tolerance) would be correlated with hours of CM.
- (3) ABCCS items related to limitations in functional ability (e.g. continence, dressing, bathing, meal preparation) would be correlated with hours of CS, but not hours of CM (e.g. the greater the functional independence, the fewer CS, but not necessarily CM hours).

### Methods

#### Procedure

Thirty case managers (companies or individuals) working in England and Scotland were invited to participate in the study. All case managers had over 2000 hours of experience working with clients with TBI and over 2000 hours as a case manager (i.e. advanced BABICM members). Of the 30 case managers who agreed to participate, 18 entered data into the system from the beginning of January 2011 to the end of February 2011, forming data set 1. Data set 2 was entered using the same procedure, but was comprised of all CM client data meeting the study criteria from a single CM company in Southeast England (Head First, Kent, UK). The above hypotheses were explored using data from these two independent data sets that included case management hours (CM) and care/support hours (CS) and the ABCCS, all of which are described below. Datasets were kept separately, as the comparability of the samples had not been established. Case managers who completed the ratings were aware that the purpose of the study was to examine factors associated with hours of CM and CS, but were blind to the specific hypotheses. Samuel Merritt University Institutional Review Board approved the study.

#### Participants

All client data from the participating CM services meeting the inclusion criteria were entered blind for analysis. Clients met the inclusion criteria if they were living in the community (i.e. not in residential or other institutional care), over the age of 12 years at the time of assessment and had sustained a TBI (vehicular, falls, assaults, sporting injuries), hypoxia, anoxia,

anaesthetic accident or a limited range of vascular events (e.g. subarachnoid haemorrhage). Clients were excluded if they had a stroke or brain injury associated with a cardiac event, as these diagnostic groups were considered to have different patterns of cognitive and functional outcomes from those seen in TBI [71]. Individuals were not excluded on the grounds of substance abuse or psychiatric impairment.

### Measures

#### Case management hours

CM services varied in type, intensity and complexity. Some clients and families required advice, guidance and support from a case manager on an intermittent basis. Other clients with a complex presentation of health, rehabilitation, care and social needs or the potential to engage in high-risk behaviour required continuing CM interventions and the co-ordination of a wide range of services from different clinical disciplines and providers. Hours of other types of therapy services (e.g. physical therapy) were not included in hours of CM or CS. All participating organizations maintained records of CM contacts with clients that included when the contact occurred, what was undertaken and the contact duration. Hours of CM were recorded for a period of 12 months prior to the date of assessment. Reports of CM hours were stratified into the following ranges: very low (1–50 hours per year), low (51–100 hours per year), medium (101–150 hours per year), high (151–250 hours per year) and very high (> 250-hours per year). These ranges were selected on the basis of the CM experience of one author (JCW) who has worked with this client group for over 20 years. The numeric mid-points of the ranges were entered into SPSS version 19 [71] for the correlational analysis.

#### Care/support hours

Fifty-three per cent of the clients in Group 1 and 43% of clients in Group 2 received an hour or more of care from family members each day. Mean paid support care hours are provided in Table I. Only hours of care provided by paid support workers were included in the correlational analysis.

CS hours could be allocated to meet a variety of client needs including (a) to implement the clinical and therapeutic recommendations of the treatment team, (b) to provide physical assistance, prompting or supervision for ADLs and social support for activities in the home and community and (c) to reduce the risk of engagement in dangerous or harmful behaviours by providing supervision and redirection for clients with emotional and behavioural dysregulation.

Participating organizations kept records of paid CS hours provided to each client. Hours of paid CS per week (if this was stable) or an average of weekly CS hours over a month were entered into the online system. Hours of paid daytime CS were stratified into eight categories: no care, 0–10 hours per week, 11–25 hours per week, 26–48 hours per week, 49–70 hours per week, 71–112 hours per week, 113–168 hours per week and over 169 hours per week (see Table II). Night CS hours were stratified into four categories as follows: no night care, occasional sleep-in care (16 hours), care from

Table I. Care and case management.

Variable	Group 1 (n = 76)	Group 2 (n = 65)	p-value
	n (%)	n (%)	
<i>Family Care/support</i>			
No family care	12 (16)	26 (40)	0.027
Less than 1 hour per week	6 (7)	4 (6)	
Less than 1 hour per day	18 (24)	7 (10)	
Over 1 hour per day	40 (53)	28 (43)	
<i>Total CM hours</i>			
< 50	22 (29)	18 (28)	0.001
51–100	24 (32)	12 (18)	
101–150	16 (21)	7 (11)	
151–250	9 (12)	6 (9)	
> 250	5 (6)	22 (34)	
<i>Weekly CS hours</i>			
	n = 70	n = 58	
Mean total care hours	47.8	73.9	< 0.05
Mean day care hours	36.8	57.3	< 0.05
Mean night care hours	10.27	18.2	< 0.05

one person overnight (56 hours) and waking care from two people (112 hours). Numeric mid-points for each range of day and night hours were added together and used as ‘total care hours’ for the correlational analysis.

#### *Adaptive behaviour and community competency scale*

The Adaptive Behaviour and Community Competency Scale (ABCCS) [73] was selected because the ratings provide ordinal scales designed specifically to be sensitive to the types of issues experienced by persons with TBI in the post-acute period. It records data primarily at the level of impairment and ability [74] and has been demonstrated to be reliable and valid when used with a UK community population [73].

Items are ‘criterion-keyed’ and relate to the types of behavioural and functional skills necessary for community living. Where appropriate, scales were developed based on theoretical principles. For example, the scale ‘Insight’ was based on the descriptive theory of Crosson et al. [75] in which self-awareness is described as hierarchical: intellectual awareness at the bottom, emergent awareness next and anticipatory awareness at the highest level. Overall, inter-class correlation coefficients for inter-rater and test–re-test reliabilities have been shown to be excellent (ICC = 0.9681 and 0.9860, respectively). Item reliabilities for Kappa [76] varied for each domain. For the Functional items, inter-rater reliabilities were predominantly good-to-excellent (poor = 5%, fair = 41%, good = 48%, excellent = 23%); Functional-Cognition items were predominantly fair-to-good (poor = 9%, fair = 48%, good = 43%) and Behaviour Disorder items were fair-to-excellent (fair = 52%, good = 26%, excellent = 22%). An additional ‘behavioural predictability’ item was developed and an initial inter-rater reliability analysis on this item on a sub-set of the Group 2 clients (n = 30) yielded a Kappa in the fair range (0.40–0.60) [76].

#### **Data analysis**

SPSS version 19 [72] was used for all analyses. Descriptive statistics (frequencies and percentages) were used to examine

the client demographics. Student *t*-tests were used for continuous data and Chi-square or Cramer’s V for categorical data, as appropriate, in order to determine if the two data sets differed significantly in relation to demographic factors, severity of impairment, and severity of outcome (see Table III). Mann-Whitney analyses were conducted to examine the degree to which the client ratings on the ABCCS items differed between data sets. Spearman’s Rho was used for all correlation analyses that included the ordinal ABCCS items. The authors were primarily interested in the degree to which the use of CM and CS hours were associated with item rankings on the ABCCS scales of Functional Skills, Functional-Cognition and Behaviour Disorder. Because the study is exploratory, multiple comparisons were made, thereby increasing the risk of finding chance associations. To reduce the chance of type I error, only significant ( $p < 0.05$ ) correlations of  $> 0.2$  that occurred in both datasets are discussed.

## **Results**

### **Client characteristics**

Client demographics, severity of injury and indicators of severity of outcome for Groups 1 and 2 are provided in Table III. There were no significant differences between the groups in terms of age, age at time of injury or gender. Group 2 clients were, however, significantly further post-injury, were less likely to be employed or in education and, at the time of the assessment, had received more years of CM. As is typical for studies of persons with TBI who are significantly post-acute, indications of severity of injury were incomplete [3]. Scores on the GCS were available for the majority of clients in both groups and did not differ significantly between groups. Coma duration was available for 30 clients (40%) in Group 1 and for 37 clients (57%) in Group 2 and indicated coma duration was on average significantly longer for clients in Group 2 (see Table III). Estimates of PTA were available for 31 clients (41%) in Group 1 and for 42 clients (65%) in Group 2 and indicated that PTA was, on average, significantly longer for clients in Group 2. Group 2 had a greater percentage of clients with PTA in excess of 7 days (see Table III). Annual CM hours were also significantly higher for clients in Group 2.

Table I presents hours of CM and hours of CS for groups 1 and 2. Table II presents the item ranges, median of the ABCCS items, the percentage of clients who were independent (or achieved the highest rating level) on the ABCCS items for groups 1 and 2 and compares the means for overall differences on ABCCS item scores in each group. The majority of clients in both groups 1 and 2 were continent (Group 1, 79%; Group 2, 84%). Most clients in both groups were rated as unable to prepare complex meals (Group 1, 11%; Group 2, 19%; rated as independent in complex meal preparation). Clients in both groups had high rates of behaviour dysregulation. In Group 1, 68% engaged in verbal aggression and 27% engaged in physical aggression. In Group 2, 77% engaged in verbal aggression and 34% engaged in physical aggression. Looking in more detail at the frequency of aggression in Group 1, 43.2% engaged in verbal aggression and 8% engaged

Table II. Range, median and percentage independent on ABCCS items for Groups 1 and 2.

ABCCS variable	Item range	Group 1 (Median)	Group 1: Percentage independent (no impairment) (n = 76)	Group 2 (Median)	Group 2: Percentage independent (no impairment) (n = 65)	Mann-Whitney U comparing Groups 1 to 2 item scores
<i>Functional items</i>						
Continence	0–5	5.00	84%	5.00	79%	0.45
Dressing	0–4	4.00	53%	3.00	48%	0.60
Bathing	0–4	4.00	51%	3.00	48%	0.65
Eating/drinking behaviour	0–3	3.00	72%	3.00	71%	0.66
Indoor mobility	0–6	5.00	73%	5.00	63%	0.85
Meal preparation (complex)	0–3	2.00	11%	2.00	19%	0.71
Street crossing	0–4	3.00	45%	3.00	34%	0.10
<i>Functional-cognition items</i>						
Attention	0–3	2.00	8%	2.00	15%	0.39
Appointment keeping	0–3	1.00	7%	0.00	17%	0.38
Insight	0–3	2.00	11%	2.00	26%	0.01**
Impulsivity	0–7	5.00	30%	6.00	34%	0.87
Anxiety	0–5	5.00	54%	5.00	54%	0.55
Consideration of others	0–3	1.00	23%	1.00	22%	0.60
<i>Behaviour items</i>						
Response to direction	0–4	2.00	13%	3.00	17%	0.10
Predictability	0–3	2.00	20%	2.00	25%	0.83
Verbal aggression type	0–6	5.00	32%	5.00	28%	0.95
Verbal aggression frequency	0–3	2.00	32%	2.00	23%	0.60
Physical aggression type	0–9	8.00	71%	9.00	72%	0.91
Physical aggression Frequency	0–3	3.00	73%	3.00	66%	0.47
Frustration tolerance	0–3	1.00	20%	1.00	17%	0.57
Telephone etiquette	0–2	2.00	77%	2.00	74%	0.47
Handicapping social behaviour	0–10	10.00	71%	10.00	72%	0.93
Opportunistic behaviour	0–6	6.00	68%	6.00	66%	0.49
Sexual behaviour	0–6	6.00	76%	6.00	74%	0.53
Miscellaneous disturbed	0–10	10.00	95%	10.00	88%	0.13

\*\*  $p < 0.01$ .

High scores on ABCCS items indicate independence and lower scores indicate dependence.

in physical aggression one or more times per week. In Group 2, 44.6% engaged in verbal aggression and 4.6% engaged in physical aggression one or more times per week. The ratings of clients' insight were the only ratings in which there was a statistically significant difference between the two datasets ( $p = 0.01$ ). In Group 1, 11% and Group 2, 26% of clients were rated at the highest level of insight on the ABCCS item *Insight*.

### Correlational analysis

Table IV provides the correlations between demographic variables and hours of CM and CS for both Groups 1 and 2. There was a significant correlation in both groups between both GCS score and coma duration and CS: other relationships were not

consistent across groups. Correlational analyses were computed for all 81 Functional Skills, Functional-Cognition or Behaviour Disorder items on the ABCCS. Only the 26 items meeting the criteria of a Spearman's Rho correlation of 0.2 or above and with a  $p$ -value of 0.05 or less are provided in Table V.

Most correlations were found to be weak-to-moderate [77]. ABCCS ratings of *Response to direction* (Group 1 =  $-0.23$ , Group 2 =  $-0.34$ ) and *Predictability* (Group 1 =  $-0.44$ , Group 2 =  $-0.35$ ) showed some of the strongest correlations with CM. *Insight* was related to both CM and CS hours (Group 1 CM =  $-0.34$ , CS =  $-0.34$ ; Group 2 CM =  $-0.30$ , CS =  $-0.49$ ). Behaviour Disorder items were predominantly related to CM and to a lesser degree CS. Functional skills items on the ABCCS were predominately related to hours of CS and not to hours of CM.



Table III. Demographic and clinical characteristics of case management in Groups 1 and 2.

Variable	Group 1 (n = 76)		p-value
	Mean ± SD	Mean ± SD	
Age	33.37 ± 13.3	37.5.9 ± 12.1	0.06, ns
Age when injured	25.8 ± 14.8	25.3 ± 12.3	0.83, ns
Years post-injury	7.7 ± 5.1	12.17 ± 6.2	0.001
Years of CM	3.5 ± 2.9	5.7 ± 4.6	0.001
Not in education or employment	n (%)	n (%)	
Pre-injury	8 (10)	7 (10)	0.46, ns
Post-injury	47 (61)	54 (83)	0.01
Gender	48 (63)	45 (69)	0.448, ns
Male			
GCS score	n = 43	n = 50	
3–8	31 (72)	43 (86)	0.21, ns
9–12	5 (12)	4 (8)	
13–15	7 (16)	3 (6)	
Coma duration	n = 30	n = 37	
< hour	0 (0)	2 (5)	0.02
1–24 hours	2 (6)	1 (3)	
2–7 days	13 (43)	5 (14)	
> 7 days	15 (50)	29 (78)	
Duration of PTA	n = 31	n = 42	
< hour	1 (3)	0 (0)	0.01
1–24 hours	4 (13)	0 (0)	
2–7 days	10 (32)	7 (16)	
> 7 days	16 (52)	35 (83)	

**Discussion**

Although data related to severity of injury is incomplete for both Groups 1 and 2, there are indications that clients in Group 2 had more severe injuries (longer coma and PTA duration) than clients in Group 1. Group 2 clients were significantly more post-acute, were less likely to be in education or employment, had received CM services for longer, had less family support and had more CM and slightly more CS support. The ABCCS item *Insight* was the only item with a score that differed significantly between the two datasets (see Table II). As was noted previously, only correlations meeting criteria and present in both datasets are discussed.

- Hypothesis 1: ABCCS items considered to relate to EF (i.e. *Insight, Response to direction, Predictability, Impulsivity*) would be predictive of hours of CM, but not CS. The hypothesis was partially supported. All four items

Table V. Correlations between ABCCS item scores and hours of case management and hours of care in Groups 1 and 2: only variables with at least one significant correlation are shown.

ABCCS variable	Group 1 (n = 76)		Group 2 (n = 65)	
	CM hours	CS hours	CM hours	CS hours
<i>Functional items</i>				
Contenance	ns	-0.31*	ns	-0.36**
Dressing	ns	-0.44**	ns	-0.35**
Bathing	ns	-0.43**	ns	-0.50**
Eating/drinking behaviour	ns	-0.34**	ns	-0.44**
Indoor mobility	ns	-0.25*	ns	ns
Meal preparation	ns	-0.36**	ns	-0.41**
Street crossing	ns	-0.35**	ns	-0.61**
<i>Functional-cognition items</i>				
Attention	ns	-0.35**	ns	ns
Appointment keeping	ns	ns	-0.25*	-0.29*
Insight	-0.34**	-0.34**	-0.30*	-0.49**
Impulsivity <sup>a</sup>	0.27*	ns	0.25*	ns
Anxiety <sup>a</sup>	0.25*	ns	ns	0.30*
Consideration of others	ns	-0.34**	-0.27*	-0.27*
<i>Behaviour items</i>				
Response to direction	-0.23*	-0.32*	-0.40**	ns
Predictability	-0.44**	ns	-0.35**	ns
Verbal aggression type	-0.30**	ns	-0.41**	-0.32*
Verbal aggression frequency	-0.36**	-0.29*	-0.40**	ns
Physical aggression type	-0.27**	ns	-0.35**	-0.30*
Physical aggression frequency	ns	ns	-0.40**	-0.27*
Frustration tolerance	-0.39**	ns	-0.40**	ns
Telephone etiquette	-0.27*	ns	-0.31*	-0.39**
Handicapping social behaviour	ns	-0.27*	ns	ns
Opportunistic behaviour	-0.34**	ns	ns	ns
Sexual behaviour	ns	ns	-0.39**	-0.34*
Miscellaneous disturbed	-0.27*	ns	ns	-0.34*

\* p < 0.05; \*\* p < 0.01.

Correlations of interest are predominantly negative with lower ABCCS scores associated with higher levels of CM and CS.

<sup>a</sup> Higher scores on the anxiety and impulsivity scales are associated with higher levels of anxiety and impulsivity; therefore, correlations of interest for CM and CS are positive for these scales: greater levels of anxiety/impulsivity are associated with higher CM (group 1) and higher CS (group 2).

correlated with CM in both groups. However, *Insight* was also correlated with CS in both groups and *Response to direction* was correlated with CS in Group 1.

Table IV. Correlations between CM hours, CS hours and demographic variables in Groups 1 and 2.

Demographic variable	CM Group 1		CM Group 2	
	CM hours	CS hours	CM hours	CS hours
Age	-0.18 (n = 76)	0.01 (n = 67)	-0.18 (n = 65)	0.11 (n = 54)
Age at injury	-0.44 (n = 76)	-0.14 (n = 67)	-0.04 (n = 65)	0.11 (n = 54)
Years post-injury	0.05 (n = 76)	0.42*** (n = 67)	-0.41** (n = 65)	-0.73 (n = 54)
GCS score	0.22 (n = 43)	-0.32* (n = 38)	-0.06 (n = 50)	-0.36** (n = 43)
Coma duration	0.11 (n = 30)	0.38* (n = 26)	0.11 (n = 37)	0.422* (n = 29)
PTA duration	0.11 (n = 31)	0.04 (n = 27)	-0.03 (n = 42)	0.288 (n = 35)
Years of case management	0.11 (n = 76)	0.39*** (n = 67)	-0.28* (n = 65)	0.03 (n = 54)
Care total week	0.20 (n = 67)	1.00 (n = 67)	0.43*** (n = 54)	1.00 (n = 54)
Case management	1.00 (n = 76)		1.00 (n = 54)	

\* p < 0.05; \*\* p < 0.01; \*\*\* p < 0.001.

The only other ABCCS item that could be considered to relate to EF and correlated with CM was *Telephone etiquette* (i.e. an item in the ABCCS that captures unnecessarily repetitive or inappropriate phone use). It was considered that this item could also relate to self-regulation skills.

- Hypothesis 2: ABCCS items relating to behaviour disorders (i.e. *Verbal aggression: type and frequency; Physical aggression: type and frequency; Frustration tolerance*) would be correlated with hours of CM, but not CS.

This hypothesis was partially supported. Most behaviour disorder items correlated with CM, as predicted. However, *physical aggression frequency* did not correlate with CM hours in Group 1. CS correlated with *Verbal aggression frequency* in Group 1 and CS correlated with *Verbal aggression type, Physical aggression type* and *Physical aggression frequency* in Group 2. In no case did a Behaviour Disorder item correlate with CS in both groups.

- Hypothesis 3: ABCCS Functional Skills items (e.g. *Continence, Dressing, Bathing, Eating and drinking behaviour, Indoor mobility, Meal preparation, Street crossing*) would be correlated with hours of CS, but not hours of CM.

This hypothesis was supported. ABCCS Functional Skills items were correlated with hours of CS and there were no correlations that met criteria between any functional items and CM in either data set.

The correlation between CS and the ABCCS item *Consideration for others* in both groups was not predicted. This item rates a client's ability to engage with others about another's interests and to act in ways that help others.

The present analysis does not allow for all the possible factors that may underlie the current findings to be distinguished. Clinical experience would suggest that high levels of CM usage are required for clients who set unrealistic goals and who act with little or no planning, often leading to chaotic lifestyles. Such clients may not appreciate the needs of others, may not understand their own limitations and may be unable to take advice or constrain their behaviour, based on the recommendation of others. The correlations relating to CM and *Lack of insight, Consideration of others, Unpredictability* and *Response to direction* would offer some support for this view. Changes in daily life, which the individual would have previously managed without difficulty, can lead to extreme frustration and anxiety, for which an immediate resolution is sought [78,79]. The behaviour may be characterized by loss of emotional control, disinhibition, frequent mood changes and irritability and be associated with lower levels of community integration [2]. Such patterns of behaviour emerge over time and may not be apparent early in the recovery process or at any stage during interview. Interestingly, CS hours may not be elevated in this group.

Individuals with few ADL deficits, who have high levels of mobility and lack insight may have greater access to the community and more opportunities to engage in behaviours that may place them at risk. Individuals who expect to make independent decisions may take part in activities undertaken before the accident, without taking their changed competencies into account. Although such individuals may benefit from greater CS hours, many would not tolerate the perceived

constraints associated with CS. In contrast, for other individuals the risks are so high (safety or forensic) that CS provision is mandatory. Further analysis is required to substantiate this conjecture.

Rates of verbal and physical aggression in the datasets were considerably higher than those reported in unselected community samples of persons with moderate-to-severe TBI [43,44,66,80] with over two-thirds in both groups showing verbal aggression and at least a quarter in both groups showing physical aggression, suggesting that clients with challenging behaviour can be maintained in the community with appropriate case management [51]. Only samples of clients with TBI who were specifically selected for the presence of challenging behaviour have reported rates of verbal and physical aggression in excess of those reported here [3,51,53]. Rates of verbal aggression and poor frustration tolerance are related in both groups to CM: the relationship to CS is inconsistent. Similarly, this analysis reveals no consistent relationship with other Behaviour Disorder items and CS.

It is not surprising that CS relates to ABCCS ratings of mobility and personal and domestic activities of daily living. The dissociation between CS and CM hours in both datasets reported here on these variables (i.e. that ADL deficits are significantly correlated with to CS but not CM) is similar to the findings of Diwan [66], who found that ability to perform self-care tasks was inversely related to case management hours. The relationship between CS and *Consideration of others* was not expected and may suggest that extra CS support is related to the client's inability to make and maintain interpersonal relationships.

### Limitations

This study considers the hours of CM and CS provided to clients with predominantly moderate-to-severe TBI living in the community in the UK. It is a cross-sectional 'snapshot' in time. Case managers experienced in working with persons with TBI are rarely available in statutory services and data was collected from private case managers. The data reported in this paper do not provide direct evidence for the association between severity of TBI and deficits identified on the ABCCS: the latter might also be influenced by personality traits, coping style and the client's environment among other factors. Variables that might influence CM, such as lack of insight, have been inconsistently associated with severity of injury in previous studies [20,22,23]. Consistent with these findings, only weak and non-significant correlations were observed between indicators of severity of injury and CM in both Group 1 and 2 in the present study [20,22,23]. In contrast, the need for CS is at least moderately correlated with both GCS score and coma duration in both samples, a finding that is highly suggestive that severity of injury is a factor that contributes to the need for services *per se* in these populations. Individuals with on-going severe problems in community living are likely to continue to need both CM and CS services and are, therefore, retained on caseload and over-represented in the current study, particularly in Group 2. The referral bias in the Group 1 sample is unknown. Group 2 clients represented the total population served by a single CM service meeting the inclusion criteria. The similarity between

the clients in both groups suggests that they may well be representative of the population of private sector CM clients in the UK.

Although observational rating scales are prone to observer bias, the ABCCS has been shown to have high reliability, even when used by unqualified care staff with limited exposure to the scale [73]. It is probable that observer bias was reduced in the current study, as only experienced case managers who knew their clients well and had significant TBI-related experience completed the ratings. Case managers were licensed or registered in the areas of healthcare, disability or social care (e.g. occupational therapy, physiotherapy, social work, nursing) and advanced members of BABICM.

This study did not control for multiple correlations statistically, but chose to limit this source of error by interpreting only those findings that met criteria and were present in the two independent datasets. Correlations were predominantly weak-to-moderate. Findings indicate that multiple factors contribute to both hours of CM and CS in this moderately-to-severely impaired TBI population. It is probable that correlations were weak-to-moderate because of the multiple contributory factors that may influence the use of CM and CS in these clients. Use of the second dataset, as a test of the correlations established in the first dataset, lends support to the idea that the findings were not obtained by chance alone.

This study accessed the relationships between paid CS and other variables. There were only general estimates of the number of hours of family care provided. Nearly half of the clients received over an hour of family care per day, which would have attenuated the relationships found with CS, but also possibly with CM. It should be noted that higher CM hours were needed in group 2, who had less family support. Group 2 clients were also longer post-injury and had received more years of case management. The data reported here are correlational and inferences based on them should be made with caution. Nevertheless, findings are consistent with data reported elsewhere that, as parents are less able to provide care, the need for paid CS and CM appears to increase [64].

## Conclusions

In two UK community samples of clients with predominantly moderate-to-severe TBI recruited from private case management services, deficits on ABCCS items such as *Response to direction*, *Predictability*, were associated with high levels of CM. Deficits on ABCCS items related to functional skills and behaviour were associated with the use of CS hours. *Lack of insight* was associated with hours of both CM and CS. Despite some evidence that the Group 2 sample had more severe injuries than the Group 1 sample, rating on Functional Skills, Functional-Cognition and Behaviour Disorder items were notably similar across samples. The findings suggest that Groups 1 and 2 may be representative of those clients with predominantly moderate-to-severe TBI who receive community-based long-term case management in the UK. This study underlines the key role played by lack of insight in the need for both CM and CS.

Lack of insight, impulsivity and unpredictable behaviour may lead clients to engage repetitively in behaviours, which put them at various kinds of risk or which cause marked distress

or anxiety. Developing routines and a structured lifestyle may serve to reduce, but may never eliminate, the recurrent problems that arise in daily life for these clients and which the client cannot resolve independently. Knowing the client with TBI well in order to provide unobtrusive guidance that pre-empt these behaviours is central to the long-term community support required for clients with lack of insight. Estimates of lifetime care costs that focus on functional skills-related care needs may under-estimate the need for on-going support in those with low levels of ADL impairment, but who are compromised in terms of functional cognition, EF and insight.

## Acknowledgements

We would like to thank the following organizations and individual members of BABICM for their contributions to this study without which it would not have been possible: Anglia Case Management, Ben Holden, Brain Injury Case Management, Bush and Co, Chance For Life, Case Management Services, Coochi, Debbie Eaton Case Management Limited, Family Focused Case Management Limited, Head First, Medico Rehab Limited, Independent Case Management, Independent Case Management Services, Jacky Parker and Associates, Maggie Sargent and Associates, N-Able, The Rehabilitation Partnership, RT Disability and West Country Case Management. Data reported in this paper was presented at the International Brain Injury Association (IBIA) conference in Edinburgh, UK, 2012.

## Declaration of interest

Jo Clark-Wilson, Stephanie Seymour, Ross Tasker, Doreen Baxter and Mark Holloway are managing partner, employees or contractors with Head First, a case management company in Kent, UK. There are no other conflicts of interest.

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