Using the St Andrew's – Swansea Neurobehavioural Outcome Scale (SASNOS) to determine prevalence and predictors of neurobehavioural disability amongst traumatic brain injury survivors in the community

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ABSTRACT

Studies using the St Andrew's - Swansea Neurobehavioural Outcome Scale (SASNOS) confirm neurobehavioural disability (NBD) is highly prevalent in inpatient Neurobehavioural Rehabilitation and Stroke samples. However, a recent study amongst a Danish community sample of acquired brain injury survivors found a relative paucity of NBD symptoms; and when symptoms were present, they tended to be of mild severity. The current observational study employed the SASNOS to explore prevalence of NBD in individuals with traumatic brain injury (TBI) living in the community, the extent of survivors' self-awareness of NBD symptoms, and constructed prediction models of NBD. A de-identified data set was compiled, comprising data for 97 TBI survivors (74.2% men, mean time since injury 2.8 years). In addition to SASNOS self- and proxy-ratings, various demographic, clinical and injury related characteristics were captured. NBD was found to be highly characteristic, although severity varied depending on subtype. Statistical comparison of self-and proxy-ratings did not support reduced self-awareness regarding NBD, whereas treating the problem as one of inter-rater reliability suggested this was an issue. Executive impairment, depressed mood and sex were especially prognostic of NBD. Reasons accounting for differences in NBD between the community samples are discussed and recommendations for future research made.

KEY WORDS

Traumatic Brain Injury; Neurobehavioural Disability; Outcomes; Outcome Measurement; Inter-rater Reliability

INTRODUCTION

Neurobehavioural disability (NBD) as a consequence of traumatic brain injury (TBI) is the product of complex interactions between damaged neural systems, neurocognitive functions, and environmental factors, further modified by premorbid personality traits and post-injury learning (Wood, 2001). Symptoms of NBD can take many forms, often comprising elements of executive and attentional dysfunction, poor impulse control, altered emotional expression, labile mood, poor insight, problems of social judgment and awareness, and a plethora of personality changes that impede psychosocial recovery (Kretzer, Marwitz, Seel, and Serio, 1996; Williams, Wood, Alderman and Worthington, 2020). Challenging behaviour associated with NBD is enduring, often posing a greater impediment to community reintegration than physical limitations arising from injury (Alderman and Wood, 2013; Kelly, Brown, Todd, and Kremer, 2008).

Fortunately, there is now a substantial body of high-quality evidence demonstrating the clinical and cost effectiveness of post-acute neurobehavioural rehabilitation (NbR) in reducing poor social outcomes associated with NBD (e.g., Ylvisaker, Turkstra, Coehlo, Yorkston, Kennedy, Moore et al, 2007; Alderman and Wood, 2013; Alderman, Knight and Brooks, 2013; Oddy and da Silva Ramos, 2013). However, whilst effective means of managing NBD have been demonstrated, methods for the accurate assessment and measurement of symptoms must also be available to help clinicians assess needs and measure effectiveness of rehabilitation, as well as to enable researchers to investigate the epidemiology of this important outcome of TBI.

However, there are challenges to assessment and measurement. NBD is a heterogeneous condition comprising multiple clusters of symptoms, whereas many studies of NBD have focused on a single domain or cluster of symptoms rather than the greater range of difficulties comprising NBD. For example, Sabaz and colleagues (2014) investigated the focal domain of challenging behaviour, reporting a prevalence rate of 54% amongst 507 participants with TBI in community-based rehabilitation services. Although, the investigation of specific symptom clusters is not straightforward either, as prevalence estimates can vary considerably, likely reflecting the use of different measures and instruments, as well as researchers applying varying definitions of specific symptoms. Challenging behaviour illustrates this point well; although aggression has been described as one of the most debilitating outcomes from TBI (Fleminger, Greenwood and Oliver, 2006), reported prevalence estimates vary considerably (11-96%; Tateno, Jage and Robertson, 2003). Other examples of studies concerned with a single domain of NBD include irritability (Yang, Hua, Lin, Tsai and Huang, 2012), working memory (Manktelow, Menon, Sahakian and Stamatakis, (2017) and impaired self-awareness (Prigatano and Sherer, 2020).

Further, even though studies of single domains or clusters of symptoms provide useful insight, building an accurate representation of the prevalence of symptoms of NBD as a whole is also desirable. However, drawing information together from studies investigating clusters of symptoms to achieve this goal is problematic, as sample composition and study context can vary considerably. Additionally, meaningfully comparing results when different instruments and methodologies have been employed and/or when standardised scores are unavailable, is difficult. Thus, 'global' measures containing items that are both representative of the multiple symptoms that characterise NBD and employ the same metric to enable meaningful

comparison, are essential for building a comprehensive picture of outcome. However, whilst there are a number of measurement instruments available for this purpose, a review by Wood, Alderman and Williams (2008) concluded that many of these were unsatisfactory because they were not conceptualised to measure NBD, or had weak or unknown psychometric properties; potentially explaining why researchers have tended to investigate focal rather than global aspects of NBD. A further point to consider is that some studies rely on self-report ratings (for example, see Juengst, Nabasny and Terhorst, 2019), leading to potential threats of reliability. Namely, disorders of self-awareness and/or poor insight can be present after TBI, resulting in unrealistic self-appraisal and a tendency to understate difficulties (Spikeman, Milders, Visser-Keizer, Westerhof-Evers, Herben-Dekker and van der Naalt, 2013).

To overcome these challenges and provide an instrument to meaningfully measure NBD symptoms as a collective, Alderman, Williams and Wood (2011) developed the St Andrew's-Swansea Neurobehavioural Disability Scale (SASNOS, https://projects.swan.ac.uk/sasnos). The SASNOS contains 49 items capturing five domains of NBD (Interpersonal Relationships; Cognition; Inhibition; Aggression, and Communication), each with 2-3 domains (see Table 1). Each item comprises a statement describing a symptom of NBD, which is rated using a seven-point scale ('1 - never' to '7 - always'), with both self- and proxy-ratings based on the proceeding 2-week period. Standardised T-scores (M = 50, sd = 10) are formed for total, domain and subdomains, enabling a balanced assessment of NBD and meaningful comparison between different symptoms. Higher scores reflect greater perception of ability and fewer symptoms of NBD, with scores below 40 considered exceptional and indicative of potential rehabilitation goals. SASNOS has robust psychometric properties (see Alderman, Williams and

Wood, 2011) and various responsiveness indicators to reliably assess change in NBD symptoms over time (Alderman, Williams, Knight and Wood, 2017).

Recently, the SASNOS has been used to assess the frequency and progression of NBD symptoms amongst people with both traumatic and other types of acquired brain injury across various contexts, allowing useful comparisons to be made. These include people with acquired brain injury (ABI) in the community (Soendergaard, Siert, Poulson, Wood and Norup, 2019), stroke survivors in rehabilitation and community settings (O'Connell, Lawson, New and Stolwyk, 2019; Stolwyk, Low, Gooden, Lawson, O'Connell, Thrift and New, 2020; Stolwyk, O'Connell, Lawson, Thrift and New, 2018), and participants in neurobehavioural rehabilitation programmes (Alderman, Wood and Williams, 2011; Alderman, Williams, Knight, et al. 2017; Alderman, Williams, and Wood, 2018).

However, although symptoms of NBD are strongly associated with outcomes after TBI, it should not be expected that the prevalence and impact of symptoms will be consistent across contexts and different types of ABI. For example, severe symptoms may reasonably be expected to occur amongst people admitted into NbR programmes (at least in the early stage of admission), as admission is usually driven by the presence of challenging behaviour. In accordance with this, Alderman, Wood and Williams (2011) found that difficulties with Interpersonal Relationships (95.6%) and Cognition (97.1%) were especially prolific in their sample of NbR participants, whilst symptoms of Aggression (63.2%), Communication (50%), and Inhibition (79.4%) were more variable. As well as the occurrence of individual clusters of NBD symptoms, Alderman, Williams, and Wood (2018) were able to utilise the functionality of the SASNOS to meaningfully demonstrate how these clusters combined to form different

profiles of NBD which could not be reliably constructed drawing on results from single symptom cluster studies; 66% of their sample of NbR participants co-presented with difficulties relating to Interpersonal Relationships and Cognition, whereas evidence of co-existing clinical problems with Aggression, Inhibition and Communication were not as endemic.

Additionally, investigation of NBD amongst stroke survivors across rehabilitation and community contexts via SASNOS has been extensively undertaken by Stolwyk and colleagues (Stolwyk, Low, Gooden, et al. 2020; Stolwyk, O'Connell, Lawson, et al. 2018; O'Connell, Lawson, New, et al, 2019). Whilst it is not surprising that NBD symptoms were not as frequent or severe as those of people admitted into NbR programmes, their presence nonetheless had a negative impact on outcome overall. In a subacute inpatient sample of 82 stroke survivors (57.3% men; M = 47.2 days post stroke), Stolwyk, O'Connell, Lawson, et al. (2018) found that nearly 60% exhibited 'mild' or worse NBD in at least one SASNOS domain. Difficulties with Interpersonal Relationships (44.4%) and Cognition (52.4%) were most frequent (mild-moderate severity), while NBD associated with Inhibition (1.2%), Aggression (3.6%) and Communication (2.5%) were uncommon and tended to be of mild severity. Individuals rated as presenting with more severe NBD were also assessed as having decreased functional independence, greater cognitive impairment, and higher levels of self-reported anxiety and depression. NBD was also more prolific amongst stroke survivors who had sustained anterior lesions, with symptoms exerting a negative impact on those around them. However, even though results met expectations regarding the relatively high incidence of NBD amongst stroke survivors, Stolwyk and colleagues were surprised that difficulties with Inhibition and Aggression were less common. They attributed this finding to patients with more challenging

behaviour having been excluded by, for example, refusing to take part or being admitted to specialised behavioural units.

Subsequently, Stolwyk, Low, Gooden, et al. (2020) followed up a subsample of 27 stroke survivors in the community post-discharge from an inpatient rehabilitation unit. SASNOS self-ratings were used. Results suggested perception of NBD whilst in hospital was infrequent, with a third of the sample reporting occasional or rare problems with Interpersonal Relationships and Cognition, with smaller numbers complaining of difficulties with Inhibition, Aggression and Communication. There was little change in perceived prevalence of NBD symptoms pre- to post-discharge. Consequently, the authors suggested that NBD may have been under-reported owing to reduced self-awareness post-stroke (see O'Connell, Lawson, New, et al., 2019). However, even mild self-reported NBD was significantly correlated with greater functional dependence, anxiety, and depression during inpatient rehabilitation and with depressive symptoms at follow-up, suggesting that self-reported NBD is associated with poorer outcomes.

Another context in which the SASNOS has been used to quantify the extent of NBD is amongst ABI survivors living in the community (Soendergaard, Siert, Poulson, et al. 2019). This Danish sample comprised 32 people, most of whom identified as men (68.8%) and had sustained a severe TBI (68.8%) – but all cases were at least one year post-injury (M=19.4 months). Only one person had a proxy-rated SASNOS total score below cut-off (1 SD below the mean; T-score >40), and few were assessed as having difficulties on individual SASNOS domains. Ten (32.3%) were rated below cut-off for Cognition, four (12.9%) for Interpersonal Relationships, and one (3.2%) for Aggression. None of the sample had a proxy-rated T-Score below threshold

for Inhibition or Communication. However, despite the low frequency of NBD, proxies rated cognition as significantly poorer the longer the time since injury and when Glasgow Outcome Scale Extended Scores (Wilson, Pettigrew and Teasdale, 1998) were lower.

A lack of concordance between SASNOS self- and proxy ratings was also noted, with statistically significant differences for ten of 18 comparisons. Proxy ratings were significantly higher (indicating fewer difficulties) for Aggression and Communication, whereas the opposite pattern was found for Cognition. A secondary analysis of these data was undertaken by the present authors which involved calculating effect sizes (ES: Cohen, 1988), finding a small ES (≥ .20 to < .50) for all but two comparisons; a medium ES (≥50 to <80) was found for Communication and the '*Speech and Language'* subdomain. However, as all mean scores ultimately fell in the normal range for neurologically healthy controls, the practical and clinical significance of findings is unclear. Overall, Soendergaard and colleagues concluded that the prevalence of NBD in their sample was much lower than expected, especially given the severity of their sample. They suggested this was potentially attributable to several things, including time since injury, proxy-ratings being provided by relatives rather than rehabilitation professionals, and the possible exclusion of ABI survivors with the most severe forms of NBD. Indeed, the very low prevalence of NBD amongst this small group of predominantly TBI survivors in the community is somewhat unusual, as studies of single domain symptoms, also conducted in the context of the community, typically report high rates of symptoms at one, two, and five or more years post-injury (Stéfan, Mathé and SOFMER group, 2016).

In summary, studies of multiple symptoms of NBD using the SASNOS suggest these are highly characteristic amongst inpatient participants in NbR programmes but less so within stroke survivors in rehabilitation and community contexts, although when present is strongly associated with poor outcome. To date, only Soendergaard and colleagues (2019) have used the SASNOS to investigate concurrent domains of NBD symptoms amongst predominantly TBI survivors in the community, and their findings were unexpected given accounts of many single domain investigations. A further anomaly was that whilst comparison of SASNOS self- and proxy-ratings suggested the TBI sample underestimated their symptoms, mean scores for both groups fell in the range expected for neurologically healthy controls. Whilst acknowledgement that several factors may have undermined the findings of this study, we take the view that clarifying the extent of NBD amongst TBI survivors in the community is highly desirable as this is the long-term destination of most survivors. Understanding how different clusters of NBD symptoms co-exist, the extent to which they are accurately perceived by survivors, and what other factors are associated with them will also facilitate a better sense of what rehabilitation is required and how it is delivered. Cross-comparisons of multiple domain NBD symptoms between survivors of TBI and other forms of ABI across a range of contexts will also facilitate understanding of what factors influence NBD.

Consequently, the aim of this study is to employ the SASNOS to investigate concurrent domains and clusters of NBD symptoms in a representative sample of individuals with TBI living in the community, and to test the following hypotheses. First, in contrast to the findings of Soendergaard and colleagues (2019), we predict that our sample will present with significant NBD symptoms, consistent with the general findings from investigations of single domain and focal studies; we also anticipate that most survivors will present with multiple

clusters of symptoms, which we will compare with the studies summarised earlier. Second, consistent with previous findings regarding disorders of self-awareness and poor insight as an outcome of TBI, we assert that our sample will underestimate the prevalence and severity of NBD symptoms compared to informants who know them well (self- versus proxy-ratings). Finally, the studies described earlier that had employed the SASNOS demonstrated associations between NBD and other factors. Therefore, we will expand on this line of investigation by building statistical models to determine if demographic, injury and other related variables influence symptoms of NBD.

METHOD

Participants

An observational cohort study design was employed utilising an opportunistic sample through compilation of a de-identified data set (CW), drawing on information extracted from the case records of TBI survivors living in the community who had been assessed (conducted by RLW) at the University Brain Injury Clinic. Here, survivors are typically referred for neuropsychological assessment for medicolegal purposes and/or for advice on the management of long-term neuropsychological sequalae. Participant data was included providing that: the individual had consented for their data to be de-identified for research purposes, a diagnosis of TBI applied with no additional diagnosis of a progressive neurological condition, and a SASNOS rating (proxy, self or both) was available.

Ninety seven participants met these criteria, of whom 74.2% were men. Mean age at injury was 34.6 years (SD = 14.5, range = 12.9 – 66.5) and 37.3 years (SD = 14.0, range 18.4 – 72.0) at assessment. Mean time since injury was 2.9 years although there was considerable

variability (SD = 3.1, Range = .01 – 25.1). There were multiple causes of TBI: road traffic accident (63.9%), fall (18.6%), assault (9.3%), 'other' blow to the head (7.2%), and as a consequence of an explosion (1.0%). Severity of injury was determined by the length of post traumatic amnesia (Teasdale and Jennett, 1974), with participants classified as mild (14.6%) or moderate/severe (85.4% - 18.3% and 67.1% respectively). Pre-morbid intelligence was estimated using the Wechsler Test of Adult Reading UK (Full-scale IQ M = 88.7, SD = 10.8, range 70 – 114), with scores positively correlated ($r = .41$, $p<.001$) with number of years spent in formal education (M = 13.5 years, SD = 2.53, range 11 – 23). Prior to injury, 78.0% were in either full or part-time employment, compared to only 31.4% post-injury. Additionally, 67.0% reported being in a committed relationship pre-injury compared to 59.8% post-injury. Finally, sizeable minorities reported a pre-injury psychiatric history (26.8%), relevant medical history (17.5% such as previous alcohol dependency, investigations for epileptic seizures, chronic headaches), or history of learning difficulty, including dyslexia, or requiring additional support in school (17.5%). A few reported a previous non-progressive neurological history prior to TBI (7.2%, such as fractured skull, birth trauma, or history of a possible concussion/mild head trauma). Just over half (51.5%) of participants had one of these recorded in their clinical notes, with a small number reporting two or more (11.2%).

From the total sample, 87 proxies who knew the person referred for assessment well accompanied them to the assessment and completed the proxy version of the SASNOS. Each proxy was categorised into one of seven groups: spouse/partner (47.1%), parent (39.9%), son/daughter (4.6%), sibling (3.4%), other relative (1.1%), close friend (1.1%), care/support worker (3.4%). In contrast to TBI participants, the majority of proxies were women (75.9% proxies vs. 25.8% TBI participants); furthermore, the majority of raters in six of the seven

categories were women (e.g. 80.5% and 70.6% of spouses/partners and parents were women, respectively). Overall, 92% of survivors were rated by proxies as exhibiting at least 'mild' symptoms of NBD. Of these cases, 18.8% were rated below cut-off on a single SASNOS domain, 38.8% exhibited NBD in two domains, 30% in three, 10% in four, and 2.5% in all five.

Ethical approval for the study was granted by the Department of Psychology Ethics Committee, Swansea University.

Measures

In addition to the SASNOS (outlined previously), the following measures were utilised:

Wechsler Test of Adult Reading UK (WTAR-UK; Wechsler, 2001): A word recognition test consisting of 50 irregular words with atypical grapheme to phoneme translations. As reading recognition is relatively stable in the presence of cognitive impairments associated with neurological injury or normal ageing, performance provides an estimation of pre-morbid intellectual ability. The WTAR is scored in terms of the number of correct pronunciations, with total raw scores transformed to age-adjusted standard scores to predict IQ. The WTAR has been shown to be a valid measure of premorbid IQ after TBI which remains robust even in the face of suboptimal effort (Green, Melo, Christensen, Ngo, Monette and Bradbury, 2008). Estimated full-scale IQ was used in the current study.

Dysexecutive Questionnaire (DEX; Burgess, Alderman, Wilson, Evans and Emslie, 1996): Part of the Behavioural Assessment of the Dysexecutive Syndrome battery (Wilson, Alderman, Burgess, Emslie and Evans, 1996), the DEX consists of 20 items designed to assess commonly

reported cognitive, emotional, personality and behavioural symptoms of the Dysexecutive Syndrome. Items are rated on a five-point Likert scale ranging from 0 ('never') to 4 ('very often'), with higher scores reflecting more severe difficulties in everyday life. Self (DEX-S) and proxy (DEX-O) versions are available, with the latter typically completed by a close family member, friend, carer, or clinician. Evidence suggests individuals with TBI often rate themselves as having fewer and less severe problems relative to proxy-raters; consequently, DEX-O ratings are considered a more reliable post-morbid index of executive dysfunction. In addition, even though various factorial solutions and DEX sub-scales have been proposed, there remains a lack of consensus regarding a robust and parsimonious factor structure (e.g., Burgess, Alderman, Evans, Emslie & Wilson, 1998; Mooney, Walmsley & McFarland, 2006; Shaw, Oei & Sawang, 2015; Wilson, Alderman, Burgess, Emslie & Evans, 1996). Consequently, only total scores were considered here.

Beck Depression Inventory-II (BDI-II; Beck, Steer, Ball and Ranieri, 1996): contains 21 items assessing the severity of depressive symptoms (e.g., sadness, pessimism, and loss of pleasure) experienced during the preceding two-week period. Each item comprises a list of four statements (scored 0-3) arranged in increasing severity about a symptom of depression. Total scores between 0-13 indicate the presence of 'minimal' depression, 14-19 'mild', 20-28 'moderate', and 29-63 'severe'. The BDI has high levels of reliability and validity and is routinely used in research and clinical practice (e.g., Wang & Gorenstein, 2013).

Beck Anxiety Inventory *(BAI;* Beck, Epstein, Brown and Steer, 1988): consists of 21 items asking participants to rate how much they have been bothered by emotional, cognitive, and physiological symptoms of anxiety in the last week, using a four-point Likert type scale (0 =

'not at all' to 3 = 'severely'). Total scores between 0-7 indicating 'minimal' levels of anxiety, 8-15 'mild', 16-35 'moderate', and 26-63 'severe'. The BAI has excellent psychometric properties and is used widely in research and clinical practice (Beck, Epstein et al., 1988).

Other Variables: To provide a range of potential current and historical predictors of NBD, a range of demographic, clinical and injury related characteristics were extracted from case files and medical records (CW). These included both continuous (e.g., age at assessment, age at time of injury, time since injury, years in formal education) and binary (coded 0, 1) variables, including sex (male/female) severity of TBI categorised by duration post-traumatic amnesia (mild or moderate/severe), pre- and post-injury relationship status (in a relationship yes/no), employment status pre- and post-injury (in paid employment yes/no), and yes/no for each of the following - pre-injury psychiatric history/medical history/history of learning difficulty/neurological history.

Statistical Analysis

SASNOS scores were recoded to create an ordinal variable reflecting the presence and severity of NBD using the same criteria as used previously by Stolwyk and colleagues (2018), these being: normal >39.9, coded 0; mild 30–39.9, coded 1; moderate 20-29.9, coded 2, and severe ≤ 19.9, coded 3. To counter issues arising from deviation from normal distributions in some predictors, binary variables were created using recommended cut-offs to discriminate normal vs. abnormal scores for DEX-O (scores exceeding the 95th percentile – yes/no), BDI-II (≥ 14 yes/no) and BAI (≥ 7 yes/no).

Analyses were undertaken in three stages using SPSS v24.0 (IBM Corp., 2016). First, prevalence of NBD was determined by constructing means and standard deviations for the various SASNOS scores using proxy and self-ratings; these were also compared to results derived from the studies described earlier. Second, the extent of any reduction in self-awareness was investigated by comparing mean differences (paired t-tests) between SASNOS proxy and self-ratings. However, as there can be difficulties interpreting differences between means using statistical significance alone (Alderman et al., 2017), SASNOS proxy vs. self-rating differences were also considered in terms of effect size (ES) and interpreted using the cut-off thresholds proposed by Cohen (1988): <.20 "trivial"; ≥ .20 to < .50 "small"; ≥ .50 to < .80 "medium"; ≥ .80 "large". As a "medium" difference has been cited as corresponding to a meaningful difference, this threshold was employed here (Alderman, Williams, Knight and Wood, 2017; Alderman, Pink, Williams, Ramos, Oddy, Knight, Jenkins, Barnes & Hayward, 2019). Potential differences between SASNOS proxy- and self-ratings were further examined by considering data as agreement between raters (equivalent to inter-rater reliability). Extraneous variability from pooling data was reduced by using the ordered SASNOS categorical variables based on severity; the extent of absolute agreement between pairs of raters (proxy vs. self) were determined using weighted kappa as a means of inferring the degree of self-awareness. Kappa coefficients were interpreted in line with Altman (1991): <.20 "poor"; .21 to .40 "fair"; .41 to .60 "moderate"; .61 to .80 "good"; .81 to 1.00 "very good". As variance in scores was reduced by assigning means to one of four ordered categories, a conservative threshold of .75 was adopted to reflect an acceptable level of agreement.

Finally, a range of methods appropriate for the type of data and comparisons being made were utilised to identify potential univariate predictors of NBD. These included Pearson

correlation, point biserial correlation, t-test, Man-Whitney U test, Chi-square 'Goodness-of-Fit' test and ES. Variables identified as potential predictors were entered into a series of ordinal logistic regression analyses to determine prediction models of NBD. This method was used as it builds models using both continuous and ordinal variables, and because the dependent variable was an ordered categorical dependent variable.

RESULTS

Descriptives

Dysexecutive Syndrome ratings (DEX-O total scores) exceeded the 95th percentile for neurologically healthy controls (M = 40.9, SD = 15.5) in 57.3% of our sample with TBI. Mood disorders were also prolific, with 86.8% and 79.5% reporting mild or worse depression or anxiety respectively (BDI-II: M = 26.5, SD = 11.0, range 5 – 50; BAI: M = 18.3, SD = 18.3, range 0 – 51).

Prevalence of Neurobehavioural Symptoms

Prevalence of NBD amongst the TBI survivors as measured by SASNOS proxy-ratings are shown in table 1.

< TABLE 1 ABOUT HERE >

Overall, there were 13 different combinations of SASNOS domains. Half of the TBI survivors were categorised on just two of these 13 categories, specifically 'Interpersonal Relationships + Cognition' (27.5%) and 'Interpersonal Relationships + Cognition + Aggression' (22.5%).

At the domain level, the most frequent NBD difficulties reported were in Interpersonal Relationships (69%) and Cognition (83.9%), with most cases rated as having moderate-to-severe impairments (73.3% and 85.5%, respectively). At subdomain level, the percentage of survivors being rated as at least mildly impaired was broadly similar across the three Interpersonal Relationship subdomains (64.3 – 70.1%). However, there was a tendency for 'mild' ratings for S*ocial Interaction* and *Engagement*, whereas ratings were skewed towards the 'severe' category for *Relationships*. A similar dissociation was found for the two Cognition subdomains; difficulties with *Executive Function* were mainly categorised as 'mild-to-moderate', whereas difficulties with A*ttention and Memory* were mainly rated as 'severe'.

Less than half of survivors (40.2%) were rated as exhibiting problems with Aggression; however 66.7% of the total sample reported at least 'mild' problems with Irritability, with most of these cases being rated as 'mild-to-moderate' in severity. In contrast, problems with Inhibition (8%) were less evident, although there was large disparity between its two subdomains: only 8% of survivors were rated as having *Sexual Inhibition* problems compared to 46% for *Social Inhibition*, albeit predominantly to a 'mild' extent. Similarly, problems with Communication (18.4%) were also less evident, but there was again disparity at subdomain level; 40.2% of survivors were rated as having at least 'mild' problems with *Speech & Language* (predominantly mild in severity) compared to only 4.6% for *Mental State*.

Comparison of NBD Characteristics across Samples

< TABLE 2 ABOUT HERE >

The prevalence of NBD in NbR, stroke rehabilitation and community samples were compared (tables 2 and 3). All NbR participants were assessed as having 'mild' or worse symptoms in at least one SASNOS domain, with 72.1% reporting global symptoms of NBD in 4-5 domains. Difficulties with Interpersonal Relationships and Cognition were most evident, with 92.6% presenting with 'mild' or worse symptoms (predominantly 'moderate' or 'severe') in both these domains. Problems with Inhibition and Aggression were also very characteristic, although severity tended to be more evenly distributed from 'mild' to 'severe'.

In contrast, survivors in the stroke and community samples tended to present with focal rather than global NBD. However, whilst NBD was very characteristic of Welsh community dwellers (92%) and notable in the stroke sample (59.6%), only 32.3% of survivors in the Danish community sample reported 'mild' or worse NBD in at least one domain. As with the NbR sample, difficulties with Interpersonal Relationships and Cognition were most prolific; amongst the Welsh sample, 63.2% were assessed as having 'mild' or worse symptoms in both these domains. Unfortunately, equivalent data for the two other samples (Stroke, Danish Community) was not available. Further, the severity of problems in the Interpersonal Relationships and Cognition domains tended to be rated as mostly 'mild-to-moderate' in the Welsh Community sample, whereas severity was more evenly distributed in the Stroke sample, and predominantly 'mild' in the Danish Community sample.

Aggression was also far more prevalent in Welsh Community dwellers (40.2%;) compared to both the Danish (3.2%) and Stroke (3.6%) samples, but was less severe than observed in the NbR sample, being assessed as mostly 'mild' in severity. In contrast, few NBD symptoms in

Inhibition (0-8%) and Communication (0-18.4%) were observed across the Stroke and community samples, and when reported, tended to be 'mild' in severity.

Mean differences across the four samples were also explored (table 3), with a 'medium' ES (≤ 50) adopted as the minimum threshold for a meaningful difference (Norman, Sloan and Wyrwich, 2003). Means were lower in the NbR sample, reflecting more severe impairment than amongst the Welsh Community sample. Although this was expected, there were also similarities. Difficulties with *Social Interaction*, *Engagement*, *Executive Function*, *Social Inhibition* and *Attention and Memory* were equivalent, with ES below .50 in each instance. However, both samples exhibited mean scores below .40 for *Relationships* and *Irritability*, although the severity of symptoms was greater for NbR participants.

< TABLE 3 ABOUT HERE >

In contrast, NBD symptoms were generally more prevalent amongst the Welsh compared to stroke sample; the Welsh group had significantly lower mean ratings (i.e., more severe NBD) on nine of 12 subdomains ('medium' or higher ES). However, means for five of these were above cut-off, signifying that the clinically meaningful differences where the Welsh Community sample were more impaired were in the S*ocial Interaction*, R*elationships*, *Attention and Memory*, and *Irritability* subdomains. *Engagement* and *Executive Function* subdomain scores were comparable across the two samples, and both achieved mean ratings in the normal range for *Sexual Inhibition.*

Of greatest interest was the comparison between the two community samples. All 12 subdomain ratings were significantly lower (i.e., more severe NBD) in the Welsh than Danish sample. However, even though the Welsh mean ratings were lower for *Sexual and Social Inhibition, Provocative Behaviour, Overt Aggression, Speech & Language, and Mental State,* both samples were above cut-off. In contrast, the clinically meaningfulness of the remaining six subdomains was apparent; scores were above cut-off for the Danish sample, but below for the Welsh sample. Therefore, the two community samples were easily distinguishable by ratings in all subdomains pertinent to Interpersonal Relationships and Cognition, as well as aspects of Aggression (e.g., *Irritability*).

Concordance between SASNOS Self- and Proxy-Ratings

< TABLE 4 ABOUT HERE >

Self- and proxy-ratings (N=79) were compared to investigate potential issues regarding reduced self-awareness of NBD amongst TBI survivors (table 4). Self-ratings for two domains (Interpersonal Relationships, Cognition) and six subdomains (*Social Interaction*, *Relationships*, *Engagement, Executive Function*, *Attention and Memory*, and *Irritability*) fell below the cut-off of 40, suggesting many survivors perceived themselves as having clinically significant symptoms of NBD in those areas; although visual inspection of mean ratings suggests survivors tended to underestimate the extent of their NBD, with proxy-ratings lower for 12 of 18 scores. However, statistically significant differences were limited to one domain (Interpersonal Relationships) and two of its three subdomains (*Social Interaction* and *Engagement*). In each instance, mean proxy-ratings were significantly lower, suggesting

potential lack of self-awareness amongst survivors. Re-examining differences between self- versus proxy-ratings by ES revealed 17 'trivial' differences, and one 'small' (*Social Interaction*). Therefore, whilst there appears to be a tendency for survivors to rate themselves as having less severe NBD difficulties than those observed by proxy-raters, the size of these differences was not enough to be meaningful, at least as far as can be measured though differences between mean ratings. Given this, the concordance between self- and proxy-ratings was further examined by determining levels of absolute agreement (weighted kappa) using the ordered categorical variable representations of domain and subdomain scores (table 5).

< TABLE 5 ABOUT HERE >

Absolute concordance between self- and proxy-ratings can be interpreted as reflecting parity in acknowledgement of the presence of NBD symptoms, assuming the latter represents the 'gold standard'. Whilst table 4 displayed little evidence of meaningful differences between mean scores, table 5 suggests there was lack of parity between raters. No weighted kappa coefficient fell above the .75 threshold to indicate acceptable levels of agreement. The best level of agreement was for *Provocative Behaviour* (categorised as 'good'), but most comparisons (12 of 18) were classified as "fair" or worse. Overall, this suggests lack of agreement between proxy and self-ratings.

Predictive Models of NBD as Captured by SASNOS

Relationships between SASNOS domain and subdomain scores and a range of potential demographic, current and historical predictors were determined. Where univariate analyses suggested associations existed, variables were entered as potential predictors in ordinal

logistic regression analyses. Those subsequently shown not to contribute were excluded and analyses repeated until final models emerged that only contained variables that made a significant contribution (see tables 6-13 for final solutions).

Each set of analyses is captured across two tables. The first describes model fitting information for the 'final model', in which potential predictor variables that made a significant contribution were retained. In the interests of clarity, model fitting information regarding the intercept and 'first model', consisting of all potential predictors identified from univariate analyses, is not captured across tables 6-13 but is available as Supplementary Information (see Supplementary Material for further details. The likelihood ratio chi-square test confirms if there was a significant improvement in fit of the model tested relative to the intercept only baseline model; a significant result confirms this was the case. The Pseudo R^2 (Nagelkerke) values correspond to approximate analogues of the R^2 values generated in ordinary least squares regression which are used to summarise the proportion of variance in the dependent variable associated with the predictor variables. Goodness-of-Fit includes the Deviance and Pearson chi-square tests that help ascertain if a model exhibits good fit to the data; non-significant results indicate this is the case. The Test of Parallel Lines provides a test of the assumption that the relationship between predictor variables is the same across all possible comparisons involving the predicted variable - non-significance is interpreted as evidence that this assumption is met.

The second table pertaining to each analysis presents the parameter estimates for the final models. Regression coefficients are presented under the B column, whilst the Wald Chi-square test result confirms that predictor/s make a significant contribution to the final model.

The Exp(B) column contains odd ratios, reflecting the changing probabilities of a case falling at a higher/lower level on the dependent variable. An odds ratio greater than one suggests an increasing probability of a higher categorical classification of NBD severity as values on the independent variable increase. Likewise, an odds ratio of less than one suggests a decreasing likelihood as the independent variable increases. 95% confidence intervals for Exp(B) are also captured.

Model Fitting Information: For 17 of 18 SASNOS outputs, the likelihood ratio chi-square tests confirmed a significant improvement in fit of the final models relative to the intercept only baseline models (see Supplementary Materials for intercept and baseline model data). The only SASNOS output where this was not the case was Communication (chi-square = 3.83, P = .281) (see tables 6, 8, 10, and 13).

Goodness-of-fit/Test of Parallel Lines: Assumptions were generally met, with only a few exceptions. The Pearson test proved significant for Cognition and A*ttention and Memory* (whilst the Deviance and Test of Parallel Lines tests did not); and the Test of Parallel Lines was significant for Aggression and S*peech and Language* (whilst the Pearson and Deviance tests were not).

Pseudo R^2: Estimates of the proportion of variance accounted for by the 17 successful models ranged from 12.8% (*Speech & Language*) to 62.4% (SASNOS Total Score).

Predictor Variables: Twelve of 17 potential predictor variables were included in the ordinal logistic regression analyses, including: sex; years of education; a history of learning difficulty

prior to TBI; neurological history prior to TBI; psychiatric history prior to TBI; relevant medical history prior to TBI; BDI-II score; BAI score; DEX-O score; time since injury; in a relationship post TBI; and WTAR estimated FSIQ. The number of predictor variables entered in each of the initial 18 models ranged from two (*Mental State*) to six (Total SASNOS Score, A*ttention and Memory*). The most frequent number of variables considered in the first model was three, with the 17 successful 'Final Models' each containing one to three variables (please see the Supplementary Material for a definitive list of predictors initially entered into the ordinal logistic regression for each SASNOS output).

Prediction Models Containing a Single Variable: The most prolific was DEX-O (tables 7, 9, 11 and 13), which had a significant association with NBD severity in all 17 surviving models and was the single predictor in 10 - SASNOS total score; *Social Interaction* and *Relationships*; E*xecutive Function*; Inhibition and its two subdomains (*Sexual* and *Social Inhibition*), and Aggression and two of its three subdomains (*Provocative Behaviour*, *Irritability*).

Parameter estimates confirmed higher ratings on the DEX-O were associated with increased likelihood of being categorised as having more severe NBD. The best model was for Inhibition (table 9) - the odds of having severe inhibition difficulties increased by a factor of 1.273 for every additional rating on the DEX-O. In summary, survivors rated as having more frequent, severe symptoms of executive impairment, were more likely to be assessed as having more severe problems with Inhibition.

Prediction Models Containing Multiple Variables: Seven models contained two to three predictors; DEX-O was retained in all of these. Other predictors were sex (4/7 models), BDI-II

score (3/7 models), time since injury (2/7 models), and relevant medical history prior to TBI (1/7 models).

Table 6 confirms the final models evidenced better fit than the intercept-only models for Interpersonal Relationships (chi-square = 42.64, p<.001) and one of its subdomains, *Engagement* (chi-square = 38.27, p<.001) - both contained identical predictors (DEX-O, sex, and BDI-II score). The likelihood of being categorised with severe NBD increased with incidence of executive impairment and depressed mood, especially amongst men. Parameter estimates (table 7) confirm the odds of being assessed as having severe NBD increased by a factor of 1.090 (Interpersonal Relationships) and 1.067 (*Engagement)* for each single rating incurred on the DEX-O; and by 1.066 (Interpersonal Relationships) and 1.065 (*Engagement)* for each assessment point on the BDI-II. In addition, the odds of a man being in a higher severity category of NBD were .242 greater than a woman for Interpersonal Relationships and .161 for *Engagement*.

Additionally, final models containing DEX-O and sex also evidenced better fit to intercept-only models for Cognition (chi-square = 51.04, p<.001) and one of its subdomains, A*ttention & Memory* (chi-square = 47.03, p<.001) (table 8). The odds of being in a higher severity category of NBD (table 9) increased for each scale point conferred on the DEX-O by a factor of 1.115 for Cognition and 1.065 for A*ttention & Memory*. There were also higher odds of men being categorised as having more severe NBD than women (Cognition - .231; *Attention & Memory* - .165).

Regarding Aggression (tables 10 and 11), the severity of *Overt Aggression* was successfully predicted by two variables - DEX-O and relevant medical history prior to TBI (chi-square = 18.19, p<.001). Higher ratings on the DEX-O increased the odds of presenting with more severe Aggression in general (1.116), and overt aggression particularly (1.108). Additionally, survivors with a relevant pre-injury medical history had 6.361 times the odds of subsequently presenting with increasingly severe overt aggressive behaviour.

Finally, although potential predictors were no better than the intercept-only model in predicating Communication scores, this was not the case with its subdomains (table 12 and supplementary material). Severity of NBD symptoms associated with *Speech & Language* was successfully predicted by a model which included age and DEX-O (chi-square = 9.53, p = .009). For every one-year increase in age, the odds of being categorised as having severe *Speech and Language* difficulties increased by 1.038, and by 1.035 for each additional rating/point on the DEX-O (table 13). Table 12 also indicates a model comprised of time since injury and DEX-O score was predictive of *Mental State* scores (chi-square = 6.70, p = .030), although parameter estimates revealed that neither of these variables were significant individual predictors in the model (time since injury p = .063 and DEX-O p = .700).

DISCUSSION

The first aim of this study was to use SASNOS to investigate the prevalence of NBD exhibited by individuals with TBI in the community. We hypothesised that our sample with TBI would present with significant symptoms of NBD and that most survivors would present with multiple clusters of symptoms. We confirmed this was the case, with 92% exhibiting 'mild' or worse symptoms in at least one SASNOS domain. Thus, in contrast to Soendergaard and

colleagues (2019), NBD was highly characteristic of our sample. We also conducted cross-comparison of our results with those found for stroke survivors, assessed in the contexts of rehabilitation and the community, and the Danish ABI sample. The headline prevalence rate for our sample sat intuitively where expected, falling between the rate found in NbR (100%) where people with the most extreme challenging behaviour are likely to migrate, and stroke survivors receiving rehabilitation (60%) where a mixture of posterior and anterior lesions are likely.

However, whilst NBD was highly characteristic of our Welsh sample of individuals with TBI living in the community overall, frequency and severity of specific symptoms varied considerably. 69% reported 'mild' or worse symptoms with Interpersonal Relationships and 83.9% for Cognition, whereas only 40.2%, 18.4% and 8% reported at least 'mild' problems for Aggression, Communication, and Inhibition, respectively. Consistent with Alderman and colleagues (2011, 2017), the most common presentation was a combination of NBD symptoms from Interpersonal Relationships and Cognition (49.5% of the total sample), of which nearly half (49.5%) were also assessed as presenting with 'mild' or worse NBD symptoms of Aggression.

That said, even though NBD concerning Interpersonal Relationships and Cognition appear generally characteristic of ABI, symptoms were highly non-homogeneous, with disparity commonly observed at subdomain level. For example, whilst 92% of our sample were assessed as being in the 'normal' range for Inhibition, few survivors were assessed as having *Sexual Inhibition* difficulties (3.4%), but nearly half (46%) were rated as exhibiting difficulties with *Social Inhibition*. Likewise, 40.2% of our sample were assessed as having 'mild' or worse

difficulties with Aggression; but 66.7% were rated as having 'mild' or worse difficulties with *Irritability*, the majority (75.7%) of which were 'moderate-to-severe'. Similar dissociations were also found within the Communication and Cognition domains, further highlighting the need to consider both domain and subdomain scores. Difficulties with *Relationships*, *Attention and Memory*, *Social Inhibition*, *Irritability* and S*peech and Language* were also especially noteworthy; 13 different combinations of SASNOS domains were found which broadly parallels the 10 reported by Alderman et al. (2011). Breaking down SASNOS profiles by subdomain in a large mixed-aetiology ABI sample to identify the range and principal types of NBD profiles would be a useful objective for future studies.

Further, the high overall prevalence rate of NBD in our sample contrasted sharply with the result of 32.3% described by Soendergaard et al. (2019). In the Danish sample, symptoms of NBD were relatively infrequent and predominantly of 'mild' severity. In contrast, nearly all survivors here (92.0%) presented with NBD symptoms in at least one SASNOS domain, and most two or more (74.7% of the total sample, with 81.3% of those assessed as having 'mild' NBD on at least one domain). Severity was also more variable, ranging from 'mild' to 'severe' depending on type. Sample representativeness may help to explain these findings, as Soendergaard and colleagues reasoned that the lack of NBD observed in their sample may have been because survivors with the most severe symptoms had been excluded. Interestingly, Stolwyk and colleagues (2018) suggested this was also the case with their stroke sample, helping to account for the low levels of aggression and disinhibition observed. Alternatively, increased levels of NBD in our sample may be attributable to those survivors with greater difficulties seeking help or financial compensation. Although, results from studies investigating focal NBD symptoms in community samples suggest that such difficulties

are present, validating our findings. For example, high rates of challenging behaviour have been reported in both community ABI (85% - Kelly et al., 2008) and TBI (54% - Sabaz et al., 2014) samples; and Rabinowitz and Levin (2014) reported that approximately 65% of survivors with moderate-to-severe TBI experience long-term cognitive impairment, with as many as 15% of mild cases also reporting persistent problems. High rates of alexithymia and low levels of emotional empathy are also commonly described (Williams and Wood, 2010; Wood and Williams, 2007 and 2008), with the resulting lack of emotional responsivity, mutual support, and reduction in overt acts of affection contributing to the fragility of close personal relationships and diminishing social networks after injury (Williams and Wood, 2013; Williams et al., 2020). This may help explain why scores on the Cognitive and Interpersonal Relationships SASNOS domains are often reported as being the lowest across studies, as the latter difficulties may be driven to a large extent by social cognition difficulties.

Other factors may also help explain the different rates of NBD across the two community samples. First, there is a difference in time since injury: mean 1.62 years for the Danish sample vs. 2.8 years for the Welsh sample (ES = .43). A consistent finding in the literature is that NBD is enduring and symptoms can increase over time (see Thomsen, 1984; Brooks, Campsie, Symington, Beattie and McKinlay, 1987; Johnson and Balleny, 1996; Alderman, 2001; Kelly and Parry, 2008; Juengst, Nabasny and Terhorst, 2019; Timmer, Jacobs, Schonherr, Spikemn and van der Naalt, 2020). Second, NBD is also especially associated with damage to anterior brain structures (Wood and Worthington, 2017). Our sample were all cases of TBI, most of whom were survivors of road traffic accidents, where the physical mechanisms of injury incurred through rapid deceleration forces on frontal brain structures are well known (Bigler, 2001 and 2007; Wood, 2001). In contrast, the Danish sample experienced a broader range of

causes of ABI (e.g., TBI, Anoxia, Stroke), with the proportion subject to rapid deceleration forces undocumented. An interesting finding from Stolwyk and colleagues (2018) in this regard was that NBD as measured by the SASNOS was higher amongst CVA survivors with anterior lesions. Finally, as NBD is the product of interaction between several key factors, including the environment and premorbid personality traits, local norms and expectations may impact on how it is expressed. Therefore, national, and cultural differences across samples may have played a contributory role. A potentially pertinent finding is that people from Denmark have been reported to be the *"…world's happiest people"* and those with Danish ancestry more likely to have a *"…positive outlook on life",* with a genetic explanation accounting for this (O'Callaghan, 2014).

The second aim of this study was to investigate parity in awareness of NBD symptoms across self- and proxy-ratings. We hypothesised that self-ratings would underestimate prevalence and severity of NBD symptoms because of disorders of self-awareness and poor insight, a known outcome of TBI (and a further symptom of NBD). Soendergaard et al. (2018) previously found mixed findings regarding the concordance between SASNOS self- and proxy-ratings. They found several statistically significant differences across ratings, but as mean scores fell within the normal range for neurologically healthy controls, the clinical significance of findings were unclear. Further, we found that calculating ES as an alternative method of analysis further undermined confidence in their findings. Results were also mixed in the current Welsh sample. Survivors generally rated themselves as having fewer difficulties than proxies, and in contrast to the Danish cohort, mean proxy-ratings for half of the SASNOS subdomains fell below the normal range, although only two comparisons were statistically significant. Additionally, ES only ranged from 'trivial' to 'small'. Taken together, both sets of

results imply differences between raters are insufficient to support a hypothesis of reduced self-awareness. However, when the issue is perceived as the extent of absolute agreement between self- and proxy-raters, weighted Kappa coefficients did not meet the minimum threshold for any SASNOS domain or subdomain. As data variance had been considerably reduced by transforming scores into ordered categorical variables, low Kappa values suggest poor self-awareness may be an issue after all. A future study using a larger cohort with greater range in SASNOS ratings would help clarify this issue.

Our final hypothesis was that it would be possible to construct prediction models of NBD from the range of demographic, injury and other related variables collected. Models consisting of one-to-three variables were successfully constructed for nearly all SASNOS outputs, with the extent of executive impairment, depressed mood and sex (male) found to be especially indicative. Consistent with this, Stolwyk and colleagues (2018) found that more severe NBD was associated with greater cognitive impairment and higher levels of self-reported anxiety and depression; and Soendergaard and colleagues (2019) found a negative correlation between time since injury and NBD in their Danish ABI community cohort. Additionally, Sabaz and colleagues (2014) previously reported that amongst men post-ABI, challenging behaviour was associated with depression. Of course, we recognise limitations in our current approach as our models were restricted to the range of opportunistic variables available. Consequently, we were unable to consider a range of factors previously identified as predictive of NBD, including known damage to anterior brain structures, premorbid difficulties with aggressive behaviour, drug and alcohol misuse, decreased functional abilities, reduced psychosocial participation and increased care needs (Sabaz et al., 2014). Consequently, future studies should consider a more comprehensive range of potential predictors. We also acknowledge

that whilst difficulties with executive function and mood are investigated here as predictors of NBD, other symptoms of NBD can influence these. The data collected here did not enable a more sophisticated analysis to be undertaken to investigate issues of directionality; this would be worthy of inclusion in future studies investigating NBD. One predictor also worthy of further study is learning difficulty, as even though this variable was not retained in our final models, it was associated with several SASNOS domains and subdomains. The proportion of the current sample reporting a history of learning difficulty prior to injury was surprisingly high (17.5%), and Chester, Painter, Ryan, Popple, Chikodzi and Alexander (2017) previously found a high self-reported prevalence rate of TBI in a forensic learning disability population. However, a potential limitation of our study is that it is generally accepted that the WTAR overestimates IQ in respondents with very low scores, a factor which may erroneously have led to learning difficulty not being retained in the predictive models. Furthermore, IQ was low for the sample overall (M = 88.7) despite the overall length of time spent in education (M = 13.5 years). This result might be interpreted as evidence that the sample was not typical, further impacting on the reliability of WTAR results here. We recommended that alternative means of estimating premorbid IQ are employed in future studies exploring predictors of NBD (see Bright and van der Linde (2020) for a detailed discussion).

At this point, it is also worth noting other potential limitations, including a further reason why our sample may not be wholly representative of the target population. Whilst the number of survivors and their significant others is comparable, and in some instances greater, than other studies utilising SASNOS to investigate the prevalence of NBD, survivors included here may have either self-referred to a head injury clinic or been referred for medicolegal assessment. Therefore, our sample may have been biased towards those with the most enduring or severe

difficulties. To ascertain representativeness, further study of NBD amongst individuals with TBI living in the community should be undertaken, ensuring participants are drawn from a wide range of contexts. Another potential limitation is the possible loss of meaningful information regarding mood and executive function because of creating binary variables. This was deemed necessary as some assumptions regarding normality of data distributions for these variables was undermined. Non-normally distributed data is not unusual in psychological research but when faced with similar challenges, future studies wishing to identify predictors of NBD might chose to manage this differently in order to retain as much information as possible (for a comprehensive review of methods to address non-normality see Pek, Wong and Wong, 2018).

To conclude, our findings suggest that NBD is highly characteristic of TBI survivors in the community, highlights the usefulness of comparing both self- and proxy-ratings of behaviour to provide valuable information regarding self-awareness of NBD, and provides useful information concerning potential predictors of NBD. Our findings also demonstrate the usefulness of SASNOS for measuring global, as opposed to focal, symptoms of NBD, and for discriminating between different neurological populations. An estimated 1.3 million people are living with the long-term effects of brain injury in the UK alone, representing a cost to the UK economy of £15 billion per year - equivalent to 10% of the total annual National Health Service budget (All-Party Parliamentary Group on Acquired Brain Injury, 2018). Therefore, if the sample examined here is representative and our results are mapped onto the national population, then approximately 1.2 million survivors in the UK could be enduring mild or worse symptoms of NBD which could reasonably be accounting for much of the associated expense. Given the considerable implications of this number to screening, rehabilitation

provision and service delivery to alleviate distress and to reduce costs, further research to confirm the representativeness of the results found here should be conducted to inform the national picture.

Disclosure of interest

The authors report no conflict of interest.

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Table 1: Prevalence of neurobehavioural symptoms amongst TBI survivors as measured by SASNOS proxy-ratings (N=87)

SASNOS Domains & Subdomains	T-Score Mean (SD)	Normal %	Mildly Impaired %	Moderately Impaired %	Severely Impaired %
Interpersonal Relationships	30.1 (15.5)	31.0	18.4	20.7	29.9
-Social Interaction	32.5 (13.2)	29.9	28.7	23.0	18.4
-Relationships	31.2 (17.4)	35.6	12.6	24.1	27.6
-Engagement	33.3 (14.7)	32.2	28.7	19.5	19.5
Cognition	26.1 (12.6)	16.1	20.7	24.1	39.1
-Executive Function	33.4 (10.8)	27.6	35.6	26.4	10.3
-Attention & Memory	21.0 (15.1)	16.1	11.5	17.2	55.2
Inhibition	53.3 (10.2)	92.0	3.4	4.6	0.0
-Sexual	62.0 (8.6)	96.6	2.3	1.1	0.0
-Social	43.2 (12.7)	54.0	34.5	9.2	2.3
Aggression	44.2 (13.4)	59.8	25.3	12.6	2.3
-Provocative Behaviour	48.0 (12.0)	71.3	23.0	5.7	0.0
-Irritability	34.7 (15.4)	33.3	21.8	28.7	16.1
-Overt Aggression	53.3 (16.2)	82.8	2.3	10.3	4.6
Communication	50.1 (11.7)	81.6	12.6	5.7	0.0
-Speech & Language	44.5 (15.3)	59.8	20.7	12.6	6.9
-Mental State	54.5 (11.0)	95.4	0.0	4.6	0.0
SASNOS Total Score	36.1 (12.0)	35.6	35.6	19.5	9.2

Table 2: Comparison of NBD characteristics across NbR, Subacute Inpatient Stroke and Community Samples

	Post-acute Residential NbR Programme[1]	**Subacute Inpatient Stroke [2]**	**Community (Denmark)[3]**	**Community (Wales)[4]**
Predominant type: Predominant Sex: Age: Time since injury:	TBI Men m40.3 yrs (sd 11.3) m10.5 yrs (sd 8.7)	CVA Men m67.6 yrs (sd 15.6) m47.2 days (sd 24.7)	TBI Men m44.9 yrs (sd 16.8) m19.4 mths (sd 10.0)	TBI Men m36.9 yrs (sd 14.1) m33.5 mths (sd 37.2)
'Mild' or worse NBD in at least one domain	100%	59.6%	32.3%	92.0%
Focal vs. global NBD	Global 72.1% rated 'mild' or worse in 4-5 domains	Focal 95.7% rated 'mild' or worse in 1-2 domains	Focal 3/5 domains rated 'mild' or worse apparent[5]	Focal 80.5% rated 'mild' or worse in 1-3 domains
Most frequently observed NBD	Cognition (97.1%) Interpersonal Relationships (95.6%) Inhibition (79.4%) Aggression (72.1%)	Cognition (52.4%) Interpersonal Relationships (44.4%)	Cognition (33.3%) Interpersonal Relationships (12.9)	Cognition (83.9%) Interpersonal Relationships (69%) Aggression (40.2%)
	Tendency to 'moderate to severe' severity for Interpersonal Relationships & Cognition; more evenly distributed for Inhibition & Aggression	Tendency for severity categories to be more evenly distributed	Predominantly 'mild' severity	Tendency to 'moderate to severe' severity for Interpersonal Relationships & Cognition; predominantly 'mild' for Aggression
Least frequently observed NBD	Communication (50%)	Aggression (3.6%) Communication (2.5%) Inhibition (1.2%)	Aggression (3.2%) Inhibition (0%) Communication (0%)	Communication (18.4%) Inhibition (8%)
	Predominantly 'mild' severity	Predominantly 'mild' severity	Aggression predominantly 'mild' severity	Predominantly 'mild' severity

Note: [1]Alderman, Williams & Wood (2011); [2]Stolwyk, O'Connell, Lawson, Thrift & New (2018); [3]Soendergaard, Siert, Poulson, Wood & Norup (2019); [4]Current study; [5]Number of domains by participants not given.

Table 3: Comparison of SASNOS subdomain scores between the Welsh Community sample and NbR, Subacute Inpatient Stroke and Danish Community Samples

SASNOS Subdomain	NbR	Subacute Inpatient Stroke	Danish Community
Social Interaction	-	.74**	1.28**
Relationships	1.03††	.53**	1.14**
Engagement	-	-	1.41**
Executive Function	-	-	1.12**
Attention & Memory	-	.95**	1.77**
Sexual Inhibition	2.74†	-	1.88*
Social Inhibition	-	1.06*	1.13*
Provocative Behaviour	.73†	1.63*	1.50*
Irritability	.59††	2.12**	1.91**
Overt Aggression	1.35†	.99*	.87*
Speech & Language	1.29†	.94*	1.11*
Mental State	1.15†	.80*	.63*

Note: ES of ≤ .50 ('medium' or higher shown); †Welsh mean score higher; ††Welsh mean score higher and below cut-off; *Welsh mean score lower; **Welsh mean score lower and below cut-off

Table 4: Concordance between SASNOS self- and proxy-ratings in the Welsh Community sample

Domains & Subdomains	Self-Ratings Mean (SD)	Proxy-Ratings (Mean (SD)	t*	P**	Effect Size
Interpersonal Relationships	32.1 (16.1)	29.3 (15.3)	1.776	.040**	.18
-*Social Interaction*	36.0 (14.2)	32.1 (13.1)	2.487	.008**	.29
-*Relationships*	30.9 (17.5)	30.2 (17.1)	0.371	.356	.04
-*Engagement*	35.3 (15.1)	32.6 (14.6)	1.797	.038**	.18
Cognition	26.7 (13.0)	25.5 (12.6)	0.904	.185	.09
-*Executive Function*	34.5 (11.2)	32.7 (10.7)	1.615	.055	.16
-*Attention & Memory*	20.6 (15.4)	20.8 (15.1)	0.104	.459	.01
Inhibition	53.2 (8.5)	53.3 (10.5)	0.042	.483	.01
-*Sexual*	61.3 (8.5)	61.7 (8.9)	0.330	.371	.05
-*Social*	43.8 (10.7)	43.4 (13.1)	0.203	.420	.03
Aggression	45.4 (14.5)	44.8 (13.8)	0.515	.304	.05
-*Provocative Behaviour*	49.0 (12.4)	48.5 (12.0)	0.403	.344	.04
-*Irritability*	38.3 (16.0)	35.5 (15.8)	1.604	.057	.18
-*Overt Aggression*	50.9 (17.8)	53.5 (16.5)	1.411	.081	.15
Communication	49.6 (12.4)	49.6 (11.7)	0.016	.494	.00
-*Speech & Language*	44.6 (14.6)	43.9 (15.2)	0.372	.356	.05
-*Mental State*	53.6 (11.5)	54.3 (11.1)	0.454	.327	.06
SASNOS Total Score	37.2 (12.4)	35.8 (12.3)	1.084	.141	.11

Note: N=79 in each group; *df = 78; **p < .50; 1-tailed probability)

Table 5: Weighted Kappa coefficients reflecting the extent of absolute agreement between SASNOS self- and proxy-ratings

Domains & Subdomains	Weighted Kappa	Strength of Agreement*
Interpersonal Relationships	.50	moderate
-*Social Interaction*	.29	fair
-*Relationships*	.44	moderate
-*Engagement*	.39	fair
Cognition	.40	fair
-*Executive Function*	.35	fair
-*Attention & Memory*	.28	fair
Inhibition	-.06	poor
-*Sexual*	.24	fair
-*Social*	-.03	poor
Aggression	.46	moderate
-*Provocative Behaviour*	.65	good
-*Irritability*	.45	moderate
-*Overt Aggression*	.00	poor
Communication	.12	poor
-*Speech & Language*	.34	fair
-*Mental State*	.29	fair
SASNOS Total Score	.43	moderate

Note: *Altman, 1991 - <.20 “poor”; .21 to .40 “fair”; .41 to .60 “moderate”; .61 to .80 “good”; .81 to 1.00 “very good”. A conservative threshold .75 was used to reflect an acceptable level of agreement.

Table 6: Results of ordinal logistic regression analysis for SASNOS Total and Interpersonal Relationships (domain and subdomains), final model solution

	Model Fitting Information				Goodness-of-Fit*		Test of Parallel Lines*
Domains & Subdomains	**Variables in final model**	**-2 Log Likelihood**	**Chi-square (df) p**	**Pseudo R^2**		**Chi-square (df) p**	**Chi-square (df) p**
SASNOS Total Score	DEX	101.61	68.37 (1) <.001	.624	Pearson Deviance	98.43 (125) .962 78.56 (125) 1.00	4.03 (2) .134
Interpersonal Relationships	Sex BDI DEX	158.87	42.64 (3) <.001	.465	Pearson Deviance	200.17 (216) .773 157.58 (216) .999	3.89 (6) .692
- *Social Interaction*	DEX	146.50	29.14 (1) <.001	.326	Pearson Deviance	113.33 (125) .289 114.67 (125) .736	1.87 (2) .392
- *Relationships*	DEX	139.89	26.24 (1) <.001	.301	Pearson Deviance	113.30 (125) .765 104.36 (125) .960	2.01 (2) .366
- *Engagement*	Sex BDI DEX	164.12	38.17 (3) <.001	.427	Pearson Deviance	191.13 (216) .888 162.73 (216) .997	7.45 (6) .281

Note: *Final model only; BDI – Beck Depression Inventory; DEX – Dysexecutive Questionnaire- proxy.

Table 7: Parameter estimates for SASNOS Total and Interpersonal Relationships (domain and subdomains), final model solution

Domain & subdomains	Variables	B	Std. error	Wald Chi-square	df	p	Exp(B)	95% confidence interval for Exp(B) Lower	Upper
SASNOS Total Score	DEX	.166	.027	39.037	1	<.001	1.181	1.121	1.244
Interpersonal Relationships	Sex	-1.420	.577	6.074	1	.014	.242	.078	.748
	BDI	.064	.024	6.703	1	.010	1.066	1.016	1.119
	DEX	.087	.020	19.652	1	<.001	1.090	1.050	1.133
- *Social Interaction*	DEX	.080	.017	23.613	1	<.001	1.084	1.049	1.119
- *Relationships*	DEX	.078	.017	20.670	1	<.001	1.081	1.045	1.118
-*Engagement*	Sex	-1.824	.589	9.945	1	.002	.161	.052	.501
	BDI	.063	.023	6.983	1	.009	1.065	1.016	1.116
	DEX	.065	.018	13.959	1	<.001	1.067	1.031	1.104

Note: Final Model results presented; BDI – Beck Depression Inventory; DEX – Dysexecutive Questionnaire- proxy.

Table 8: Results of ordinal logistic regression analysis for Cognition and Inhibition (domain and subdomains), final model solution

	Model Fitting Information				Goodness-of-Fit*		Test of Parallel Lines*
Domain and Subdomains	**Variables in final model**	**-2 Log Likelihood**	**Chi-square (df) p**	**Pseudo R^2**		**Chi-square (df) p**	**Chi-square (df) p**
Cognition	Sex DEX	138.81	51.04 (2) <.001	.507	Pearson Deviance	192.80 (154) .018 120.34 (154) .979	2.19 (4) .700
- *Executive Function*	DEX	142.56	23.77 (1) <.001	.277	Pearson Deviance	106.74 (125) .880 108.18 (125) .858	1.76 (2) .415
- *Attention & Memory*	Sex DEX	125.05	47.03 (2) <.001	.493	Pearson Deviance	187.61 (154) .034 113.25 (154) .994	2.68 (4) .614
Inhibition	DEX	21.53	26.96 (1) <.001	.561	Pearson Deviance	27.17 (83) 1.00 15.17 (83) 1.00	3.56 (1) .059
- *Sexual*	DEX	14.31	12.90 (1) <.001	.484	Pearson Deviance	15.99 (83) 1.00 12.69 (83) 1.00	0.01 (1) .969
- *Social*	DEX	95.64	31.39 (4) <.001 27.73 (1) <.001	.340	Pearson Deviance	67.60 (125) 1.00 69.24 (125) 1.00	0.02 (2) .992

Note: *Final models only; DEX – Dysexecutive Questionnaire – proxy.

Table 9: Parameter estimates for Cognition and Inhibition (domain and subdomains), final model solution

Domain/subdomain	Variables	B	Std. error	Wald Chi-square	df	p	Exp(B)	95% confidence interval for Exp(B) Lower	Upper
Cognition	Sex	-1.467	.526	8.204	1	.004	.231	.085	.629
	DEX	.109	.020	27.870	1	<.001	1.115	1.071	1.162
- Executive Function	DEX	.070	.016	20.508	1	<.001	1.073	1.041	1.106
- Attention & Memory	Sex	-1.801	.560	11.028	1	.001	.165	.057	.478
	DEX	.107	.022	22.359	1	<.001	1.113	1.065	1.164
Inhibition	DEX	.241	.072	11.067	1	.001	1.273	1.104	1.467
- Sexual	DEX	.195	.075	6.659	1	.010	1.216	1.048	1.410
- Social	DEX	.089	.020	20.851	1	<.001	1.093	1.052	1.136

Note: Final Model results presented; DEX – Dysexecutive Questionnaire – proxy.

Table 10: Results of ordinal logistic regression analysis for Aggression (domain and subdomains), final model solution

Domain & Subdomains	Model Fitting Information			Pseudo R^2	Goodness-of-Fit*		Test of Parallel Lines*
	Variables in final model	-2 Log Likelihood	Chi-square (df) p			Chi-square (df) p	Chi-square (df) p
Aggression	DEX	91.19	33.25 (1) <.001	.396	Pearson Deviance	73.79 (125) 1.00 68.37 (125) 1.00	91.19 (2) <.001
- *Provocative Behaviour*	DEX	77.88	22.47 (1) <.001	.313	Pearson Deviance	69.65 (83) .852 63.96 (83) .940	0.09 (1) .762
- *Irritability*	DEX	141.68	26.18 (1) <.001	.299	Pearson Deviance	138.94 (125) .186 105.68 (125) .894	2.17 (2) .339
- *Overt Aggression*	MH DEX	66.04	18.19 (2) <.001	.304	Pearson Deviance	126.80 (145) .859 61.41 (145) 1.00	3.94 (4) .479

Note: *Final models only; MH – Relevant Medical History pre-TBI; DEX – Dysexecutive Questionnaire – proxy.

Table 11: Parameter estimates for Aggression (domain and subdomains), final model solution

Domain/subdomain	Variables	B	Std. error	Wald Chi-square	df	p	Exp(B)	95% confidence interval for Exp(B)	
								Lower	Upper
Aggression	DEX	.110	.023	22.794	1	<.001	1.116	1.067	1.167
- *Provocative Behaviour*	DEX	.092	.023	16.042	1	<.001	1.097	1.048	1.148
- *Irritability*	DEX	.078	.017	22.116	1	<.001	1.081	1.046	1.117
- *Overt Aggression*	MH	1.850	.787	5.629	1	.018	6.361	1.380	29.332
	DEX	.103	.032	10.179	1	.001	1.108	1.040	1.181

Note: Final Model results presented; MH – Relevant Medical History pre-TBI; DEX – Dysexecutive Questionnaire – proxy.

Table 12: Results of ordinal logistic regression analysis for Communication (domain and subdomains), final model solution

Domain/subdomain	Model Fitting Information			Pseudo R^2	Goodness-of-Fit*		Test of Parallel Lines*
	Variables in final model	-2 Log Likelihood	Chi-square (df) p			Chi-square (df) p	Chi-square (df) p
Communication	TSI BDI DEX	86.21	3.83 (3) .281	.072	Pearson Deviance	157.66 (143) .190 86.21 (143) 1.00	0.70 (3) .874
- *Speech & Language*	Age DEX	159.33	9.53 (2) .009	.128	Pearson Deviance	214.94 (235) .822 159.33 (235) 1.00	10.13 (4) .038
- *Mental State*	TSI DEX	24.56	6.70 (2) .030	.258	Pearson Deviance	84.30 (74) .194 24.56 (74) 1.00	0.02 (2) .992

*Final models only; TSI – time since injury; BDI – Beck Depression Inventory; DEX – Dysexecutive Questionnaire – Proxy.

Table 13: Parameter estimates for Communication subdomains (final models), final model solution

								95% confidence interval for Exp(B)	
Domain/subdomain	Variables	B	Std. error	Wald Chi-square	df	p	Exp(B)	Lower	Upper
Speech & Language	Age	.037	.017	4.502	1	.034	1.038	1.003	1.074
	DEX	.034	.015	4.687	1	.030	1.035	1.003	1.068

Note: Final Model results presented; DEX – Dysexecutive Questionnaire – proxy.