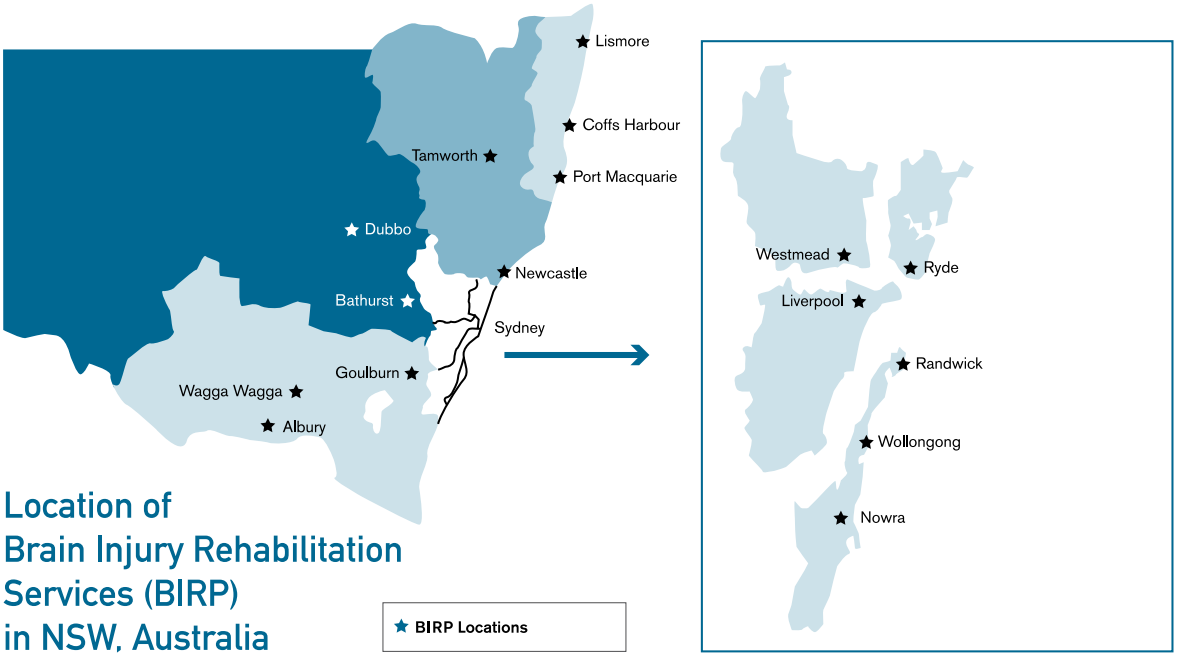
Figure 1: Locations of individual BIRP services in NSW[1].



The NSW BIRP provides inpatient, transitional and community services. Each BIRP service submits electronic demographic and clinical data for client admissions to BIRD for reporting. The CBP was able to access this information for all adult admissions to the NSW BIRP and involve clinicians from each service in the study.

[1] Newcastle and Westmead have separate adult and paediatric BIRP services. The third paediatric service is in Randwick.

METHODS

Sample

The sample for this adult study was recruited from the 11 adult services encompassed in BIRP. This included five metropolitan services in Sydney, Wollongong and Newcastle and six additional services in other parts of the state (see Figure 1). The following criteria were used to identify BIRP clients for inclusion into the study. Clients had to:

- Be community clients not inpatients
- Have had at least three occasions of service over the six months prior to recruitment into the study
- Be between 18 and 65 years of age
- Have sustained a primary traumatic brain injury (TBI)

Approval to undertake this study was provided by the Greater Western Area Health Service Human Ethics Committee, and relevant site-specific approval to undertake this study was provided by each of the services involved.

Measures

The measure used in the CBP to assess challenging behaviours was the Overt Behaviour Scale (OBS). The OBS is a well validated instrument for use in the TBI population and has been shown to capture over 90% of challenging behaviours in this group (Kelly, Todd, Simpson, Kremer & Martin, 2006). The OBS assesses nine categories of challenging behaviour: verbal aggression, physical aggression against objects, physical acts against self, physical aggression against other people, inappropriate sexual behaviour, perseveration/repetitive behaviour, wandering/absconding, inappropriate social behaviour and adynamia/lack of initiation.

The OBS requires respondents to rate the severity, frequency and perceived impact of each of the nine types of behaviours. Another four standardised and validated measures were used to collect additional information about each client, including:

- Disability Rating Scale (DRS; Rappaport, Hall, Hopkins, Belleza & Cope, 1982)
- Health of the Nations Outcome Scale – Acquired Brain Injury version (HoNOS-ABI; Wing, Beevor, Curtis, Park, Haddon & Burns, 1998)
- Sydney Psychosocial Reintegration Scale (SPRS; Tate, Pfaff, Veerabangsa & Hodgkinson, 2004)
- Care and Needs Scale (CANS; Tate, 2004)

A clinical details form was developed specifically for the CBP to obtain specific information about the services accessed or not accessed. All these forms can be found in Appendix A.

Finally, BIRD's computerised clinical dataset was accessed to obtain demographic and clinical information for each client including the date client was admitted into the BIRP, gender, age, country of birth, main language spoken, indigenous status, age at injury, time since injury, circumstance, duration of PTA and injury severity.

Procedure

Data was collected from BIRP clinicians between February 2007 and December 2008. Forms were completed by 88 clinicians identified to be the clinical informants for the clients included in the study. These clinicians were identified because they had the most complete knowledge of each of the clients.

Clinicians re-rated the OBS three months after the initial data collection if the clinical informant had at least one occasion of service with the relevant client over this same three-month interval. This re-rating was used to establish if there was any change in behaviour over time. If a clinician had not seen a client over the three-month period, they were not required to complete the OBS for the second time because it was assumed they would not have any information on which to re-rate the client.

Identification of challenging behaviour

In order to determine prevalence of challenging behaviour in clients after TBI it was necessary to develop criteria by which challenging behaviour could be recognised and counted. The OBS, the primary challenging behaviour measure in the study, was used to identify clients as challenging or non-challenging. However, it was thought inappropriate to use any of the three summary scores that can be obtained from using the OBS for this purpose because the nature of these indices is to summarise behavioural responses across the nine categories of behaviour assessed. Using these summary scores would have the unwanted effect of excluding clients as cases of challenging behaviour when their challenging behaviour was restricted to only one or a few of the nine areas assessed by the OBS.

Instead, criteria for challenging behaviour were established with reference to the objective (severity level and frequency) and subjective (perceived impact) information available for each of the nine behavioural domains assessed by the OBS. It was decided that any developed criteria should reflect the following three principles:

1. The highest levels of severity of any behaviour should be recognised as challenging regardless of the frequency. This includes unlawful behaviour or behaviour that poses a significant risk of injury or threat to the client or other people.
2. Less severe behaviours or milder forms of problematic behaviour that occur at a sufficient frequency should be considered challenging. This includes disruptive, irritating behaviours that pose a minimal risk of injury or threat to the client or others but occur at sufficient frequency to be burdensome.
3. Regardless of the objective indicators of behaviour, if behaviour is perceived to be challenging, then it would need to be recognised as such. This was considered important because perceptions in and of themselves can have a cascading effect in terms of the supports and services that need to be put in place for the client and family.

In order to operationalise the above principles, the following criteria were used to define challenging behaviour[2]:

Criterion 1:

Any OBS behaviours rated at severity level 3 or 4 were considered challenging regardless of frequency. However, for physical acts against self, physical aggression against other people and/or inappropriate sexual, perseverative and wandering behaviours of severity level 2 were also deemed challenging regardless of frequency.

Criterion 2:

Any OBS behaviours rated at severity level 1 were considered challenging if the frequency of the behaviour was rated to occur at least daily. For verbal aggression, physical aggression against objects and inappropriate social behaviours, severity level 2 was also be considered challenging if the behaviour was rated to occur at least daily. However, for adynamia/lack of initiation, at least many prompts daily were considered challenging.

Criterion 3:

If the perceived impact of any of the nine behaviours on the OBS was rated as severe or extreme, then they were considered challenging.

Table 1 illustrates the type of behaviours that were defined as challenging on the basis of the first two criteria.

Table 1: OBS cut-off criteria for challenging behaviour

	Challenging behaviour at any frequency	Challenging behaviour when occurring daily or more
Verbal aggression	4 Makes clear threats of violence toward others or self, requests help to control self	2 Makes mild personal insults but no swearing
	3 Swearing, moderate threats directed at others or self	1 Makes loud noise, shouts angrily
Physical aggression against Objects	4 Sets fire, throws object dangerously	2 Throws object down, kicks furniture without breaking
	3 Breaks objects, smashes windows	1 Slams door, scatters clothing, makes mess

[2] Because on the OBS Adynamia/lack of initiation behaviour is only rated in terms of frequency and perceived impact but not severity level, it could only be considered using criteria 2 and 3. If adynamia/lack of initiation occurred daily (criterion 2) then it was considered challenging or if adynamia/lack of initiation had a severe or extreme perceived impact (criterion 3) then is was considered challenging.

Table 1 (continued): OBS cut-off criteria for challenging behaviour

	Challenging behaviour at any frequency	Challenging behaviour when occurring daily or more
Physical acts against Self	4 Mutilates self, causes deep cuts, fracture. Includes suicide attempt	1 Picks or scratches skin, hits self, pulls hair
	3 Inflicts small cuts/bruises	
	2 Bangs head, hits fist into objects, throws self on floor (hurts self but not serious injury)	
Physical aggression against Others	4 Causes severe physical injury (fracture, cut)	1 Threatening gesture, swings at people, grabs clothes
	3 Causes mild-moderate injury (bruise)	
	2 Strikes, kicks, pushes, pulls hair	
Inappropriate sexual behaviour	4 Attempt to forcibly undress another person, threat to obtain sex, rape	1 Touching other people who don't want to be touched, kissing hand, patting knee
	3 Attempt or act of touching other people's genitals	1 Comments of a sexual nature
	2 Masturbation in public	
	2 Exhibitionism in public	
Perseveration/Repetitive behaviour	3 Engages in prolonged repetition resulting in serious physical harm	1 Engages in prolonged repetition that does not result in physical harm
	2 Engages in prolonged repetition resulted in minor physical harm	
Wandering/ Absconding	3 Escapes secure premises and may resist attempts to stop escape	1 Going into areas that are prohibited but where there is no or low risk of harm
	2 Leaves a safe place when there is risk of becoming lost or of harm	
Inappropriate social behaviour	4 Presents a danger to self or others, lights fires dangerously, crosses road recklessly	2 Nuisance/ annoyance, interrupts conversations, actively seeks attention
	4 Petty crime or unlawful behaviour, driving unlicensed, stealing cigarettes	1 Socially awkward, inappropriate laughter, failure to monitor personal hygiene, standing too close
	3 Non-compliant or oppositional	
Adynamia/ Lack of initiation[3]		Person requires many prompts daily to undertake activities of daily living

[3] Adynamia/lack of initiation is not rated in terms of severity on the OBS. It is only rated in terms of frequency. In the Challenging Behaviours Project adynamia was defined as challenging when prompting was required many time per day.

Quantitative data analysis

Non-parametric statistical tests were used to analyse the data collected. Specifically:

- Chi-squared test – to analyse the relationship between two categorical or ordinal variables[4]
- Mann-Whitney U test – to analyse the differences between two groups against a dependent continuous variable
- Kruskal-Wallis test – to analyse the differences between more than two groups against a dependent continuous variable
- Multinomial binary logistic regression – to test the ability of multiple variables to predict membership of two groups (challenging versus non-challenging behaviour)

The probability for a Type-I error of less than 5% was required for statistic relationships to be considered significant (i.e. $p<0.05$).

Qualitative case review

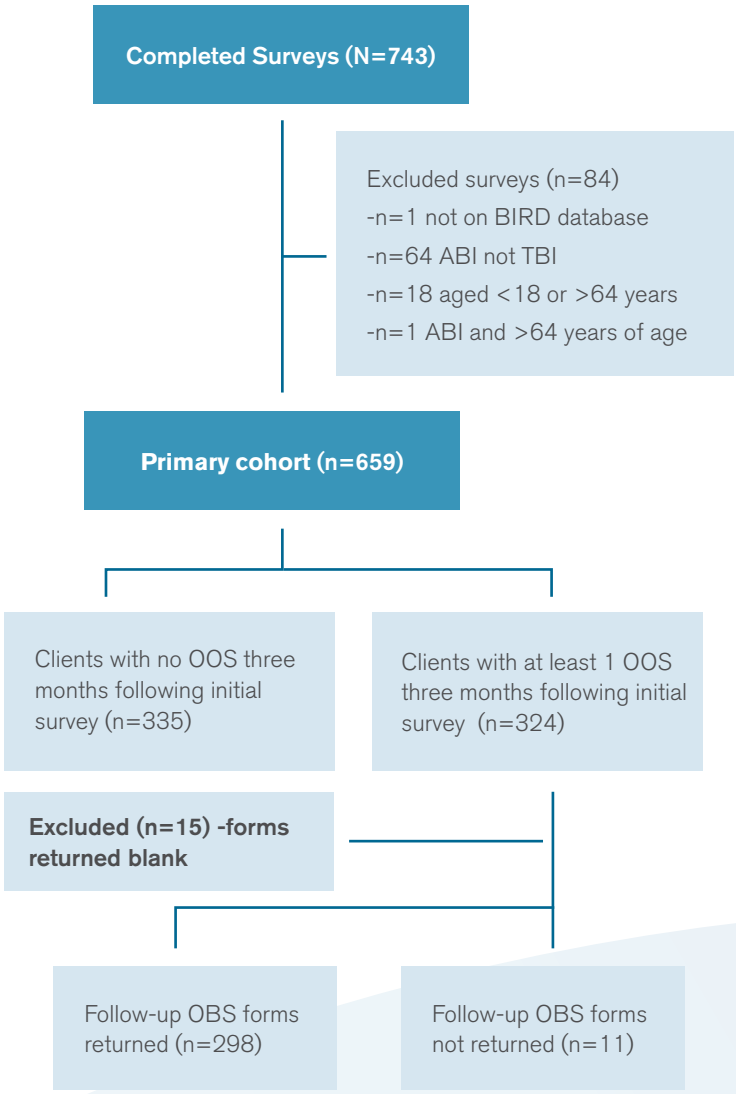
Another stage of the CBP was to have each of the 11 BIRP services identify up to four clients considered particularly challenging in terms of behaviour for qualitative review. It was expected that a thorough review of this select group of clients may provide additional information about challenging behaviours that could not be provided by analysis of the quantitative data alone.

A semi-structured interview (see interview questions in Appendix B) was undertaken with a clinician who knew the clients' challenging behaviours, treatments received and background well. Whenever convenient, sometimes before and sometimes after interview, the medical record and case notes of the clients included for qualitative review were examined to obtain background and injury details and also to gain further understanding of any behavioural issues.

The information collected from each client was then written up into a case history by either JMR or MS. In the interest of privacy these case studies have been withheld.

Each of the case histories was then read to identify themes relating to the challenging behaviours of clients who sustain TBI.

Figure 2: Flow-chart of clients included in study.



RESULTS

To determine the prevalence, co-morbidities and burden of challenging behaviours, a total of 743 BIRP clients were rated by clinician informants. However, after extraction of data from the ACI: BIRD computerised database, it was discovered that 84 clients did not meet criteria for inclusion in the study (see Figure 2). Therefore, the final client sample comprised 659 individuals.

To establish the course of challenging behaviours, clients were reassessed three months after their initial assessment. To be included in this second assessment, clients needed to have had at least one occasion of service during the three-month interval. A study flow chart is displayed in Figure 2. A summary of the demographic and clinical characteristics of the 659 clients in the study can be viewed in Appendix C.

PREVALENCE OF CHALLENGING BEHAVIOURS

The prevalence of challenging behaviour was 53.1%, representing 350 community TBI clients across the NSW BIRP network who met criteria for challenging behaviour (see Table 1).

Prevalence of different types of challenging behaviour

Aggression (including verbal and physical forms) was the most common type of challenging behaviour,shown by 31.1% of clients. Table 2 shows the prevalence of the nine different types of challenging behaviours assessed by the OBS. The three most common challenging behaviours were inappropriate social behaviour, verbal aggression and adynamia/lack of initiation.

[4] Fisher Exact tests were used when the categorical/ordinal variables had no more than two levels.