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## **Long Term Care Needs and Service Utilisation of Individuals Catastrophically Injured in Motor Vehicles in NSW**

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## **Description**

This paper presents an update on the status of a thesis examining long term care needs and service utilisation patterns of individual whom sustain a moderate to severe injury in a motor vehicle accident in NSW. A sample of 126 individuals, from four cohorts at 2, 5, 10 and 15+ years post traumatic brain or spinal cord injury have participated in a semi-structured interview during which demographic, clinical, service utilisation and life events data were collected using 10 separate instruments.

Preliminary demographic results are consistent with the profile of incidence data reported previously in terms of gender, age and level of overall function. A detailed analysis will be undertaken in the near future to model the relationship between a range of variables including levels of disability, formal and informal care requirements, service utilisation patterns, met and unmet needs. The objective of the thesis is to add to the body of knowledge in a way that can contribute to current national policy developments.

## **Location**

iC - SBS Teaching Facility

***'LONG TERM CARE NEEDS AND SERVICE UTILISATION OF  
INDIVIDUALS CATASTROPHICALLY INJURED IN MOTOR  
VEHICLES IN NSW'***

**Robert Gordon**

## **Abstract**

This paper presents an update on the status of a thesis examining long term care needs and service utilisation patterns of individual whom sustain a moderate to severe injury in a motor vehicle accident in NSW. A sample of 126 individuals, from four cohorts at 2, 5, 10 and 15+ years post traumatic brain or spinal cord injury have participated in a semi-structured interview during which demographic, clinical, service utilisation and life events data were collected using 10 separate instruments. Preliminary demographic results are consistent with the profile of incidence data reported previously in terms of gender, age and level of overall function. A detailed analysis will be undertaken in the near future to model the relationship between a range of variables including levels of disability, formal and informal care requirements, service utilisation patterns, met and unmet needs. The objective of the thesis is to add to the body of knowledge in a way that can contribute to current national policy developments.

## **Introduction**

This paper has been prepared for the Sydney Business School (SBS) HDR Student Conference, 2011. It provides a brief overview of a thesis being completed as part of a Doctor of Business Administration with the SBS.

The aim of the thesis is to explore the long term utilisation of health and related support services by individuals who sustain a moderate to severe traumatic brain or spinal cord injury. These injuries have a momentous impact on a person's life and require a complex and often expensive array of long term care and support services. Service utilisation patterns are influenced by a range of factors including the nature of a person's injury, their personal and family circumstances and the availability of appropriate services (Corrigan, 2004; High, 1995; Hodgkinson, 2000; Middleton, 2008; Pickelsimer, 2007).

The primary research question being addressed in the thesis is:

*'what are the long term care needs and service utilisation patterns of individuals sustaining a moderate to severe brain or spinal cord injury in motor vehicles in NSW and what is the cost of providing services to meet those needs?'*

## **Rationale and scope of the thesis**

Traumatic brain and spinal cord injuries have an enormous impact the lives of those who sustain them, their family and carers and the general community. Following often lengthy periods of acute care and rehabilitation, a person will begin a lifelong process of adapting and adjusting to their new situation. Support services are typically provided by both paid and unpaid carers and change over time.

Information about long term service utilisation patterns and the factors that influence them is critical in informing policy, planning and resource allocation processes. However, little research has been undertaken in this area. There is a body of work that has examined related issues such as the measurement of need, utilisation of health services, clinical outcomes as well as some limited costing work. Much of this work, however, has focussed on the short term and has not included the use of informal (or unpaid) support services.

This thesis will add to the quantum of knowledge in this field by focussing on the long term use of both formal and informal services by individuals who sustain moderate to severe and traumatic brain or spinal cord injury in the state of NSW, Australia. The variables that will be explored include the type and quantity of services utilised, perceptions of met and unmet need for services, differences in levels of functioning and the estimated cost of providing long term care services.

## **Method**

The thesis is being undertaken as a cross-sectional study of individuals whom sustained moderate and severe injuries in motor vehicle accidents in NSW at four points in time - two, five, ten and fifteen or more years post injury.

A set of ten study instruments have been selected or developed for use in the thesis as shown in Table 1. The data are primarily quantitative but are supplemented with qualitative data contained in several of the instruments.

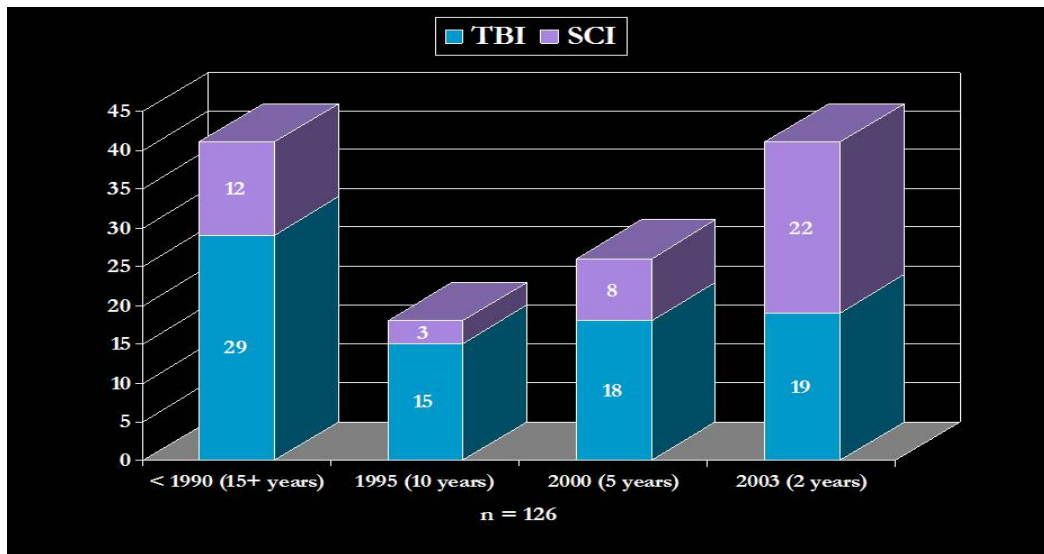
**Table 1 Study Instruments**

#	Traumatic brain injury	Traumatic spinal cord injury
1	Demographic items	Demographic items
2	Service Utilisation Questionnaire	Service Utilisation Questionnaire
3	Major life event questions	Major life event questions
4	SF36	SF36
5	Functional Independence Measure	Functional Independence Measure
6	Northwick Park Dependency Score	Northwick Park Dependency Score
7	Care and Needs Scale	
8	Caregiver Activity Survey	
9	Supervision Rating Scale	
10	Mayo-Portland Adaptability Index	

The study population is limited to cases of moderate to severe traumatic brain and spinal cord injury. Potential participants were randomly selected based on a manual search of hospital medical records.

A stratified random sampling approach was applied to ensure that the sample was representative of the population of individuals that sustain the types of injuries being studied. A standard series of steps were undertaken to recruit individuals selected in the sampling process. This involved contact information obtained from the person's medical record, telephone/internet directories and the Australian Electoral Commission. Where an individual could not be contacted through these steps, the next person on the list was selected and the process repeated.

Following recruitment of study participants, semi-structured interviews were conducted involving clients, carers and service providers across the four cohort years. A total of 126 interviews have been completed. The breakdown of the sample by injury type and cohort is shown in Figure 1.

**Figure 1 Sample size and breakdown by cohort year and injury type**

## Data analysis

A preliminary descriptive analysis of the data has recently been completed which shows clearly that a considerable body of information has been generated through the interview process. A brief summary of this is presented in the figures below. However, a significant volume of data have been collected that are not presented in this paper.

An analytic framework is currently being developed to form the basis of the next stage of the data analysis. This will explore variations in levels of disability and function, formal and informal care requirements, service utilisation patterns, met and unmet needs and a more detailed analysis of demographic variables including employment, place of residence and living arrangements.

The objective will be to develop a multivariate linear regression model in which the dependent or response variable will be the estimated cost of providing long term care services to the population of catastrophically injured individuals. A range of independent or predictor variables, based on data collected in the study, will then be analysed to assess their relationship, if any, to the cost of providing services over a person's lifetime.

## A descriptive profile of the sample

Figure 2 shows the proportion of TBI and SCI individuals interviewed. The incidence of injuries is, in fact, approximately 90% TBI and 10% SCI. The SCI (n=45) group has been over sampled to ensure a sufficient sample size. The TBI sample size is 81.

**Figure 2 Sample by injury type**

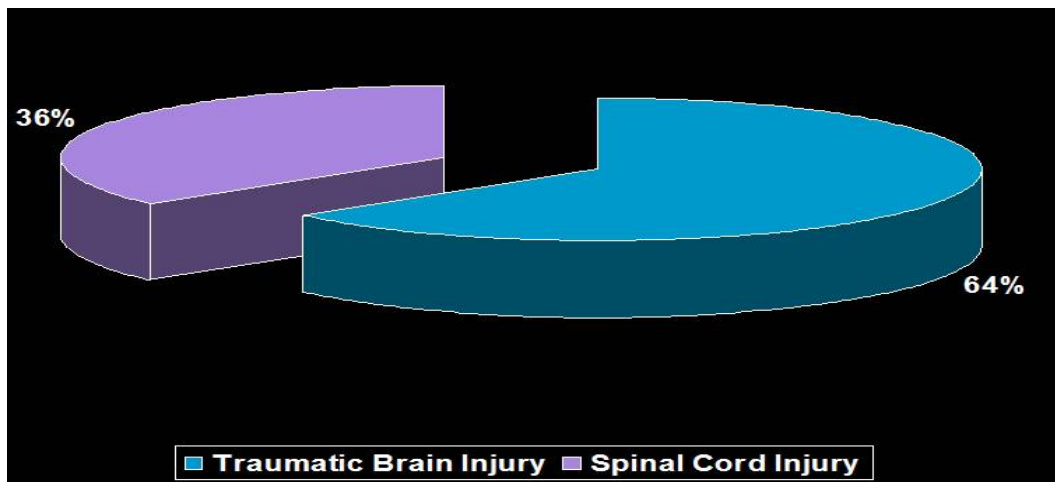


Figure 3 shows the gender breakdown across the sample. The proportion of males at 79% (n=99) and females 21% (n=27) is similar to the incidence of injuries across the population across both injury types.

**Figure 3 Gender breakdown**

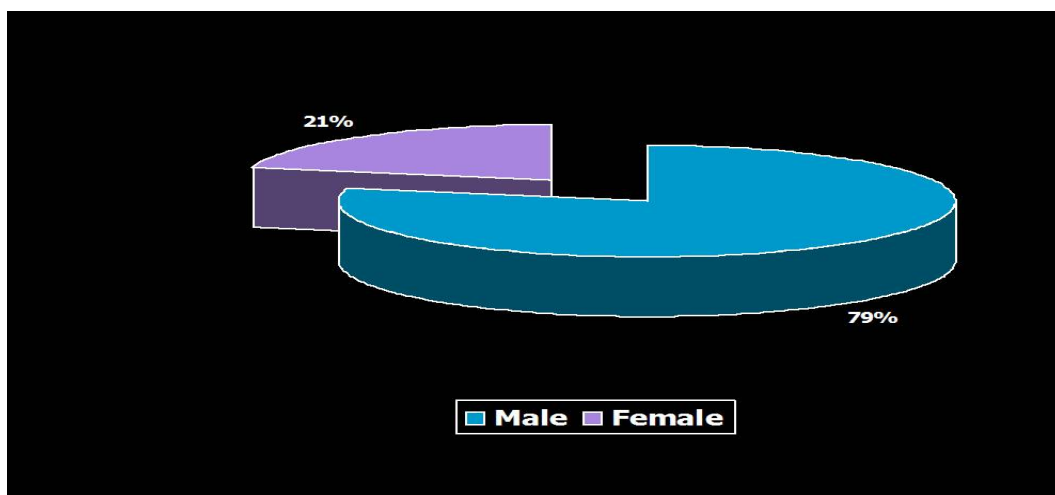




Figure 4 shows the age breakdown across the sample at the time of interview. The spread across age groups is as expected given the four study cohorts and the fact that the majority of accidents occur in the 15-25 age group.

**Figure 4 Age group breakdown**

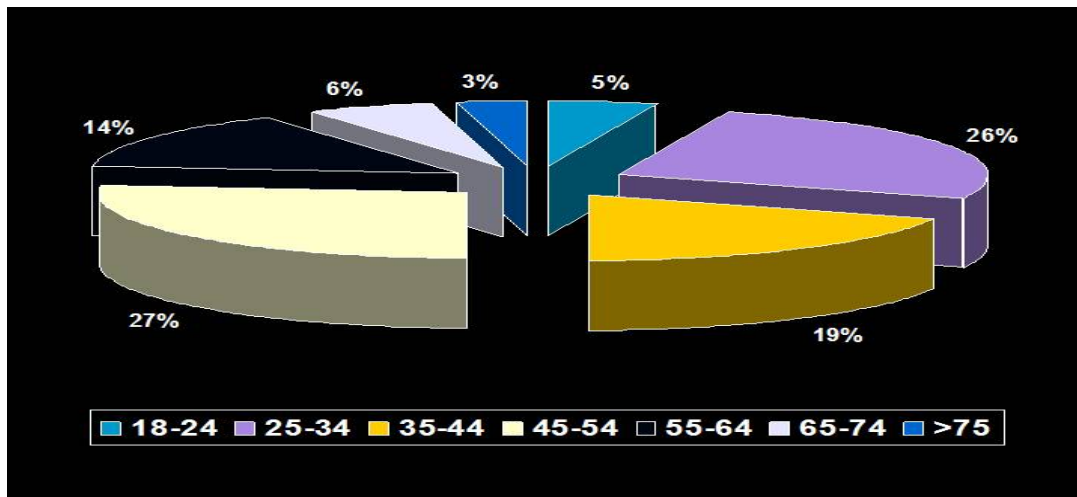


Figure 5 shows the breakdown of accommodation status across the sample. Surprisingly, 68% of individual's live in private accommodation whilst only 3% reside in institutional settings.

**Figure 5 Accommodation status breakdown**

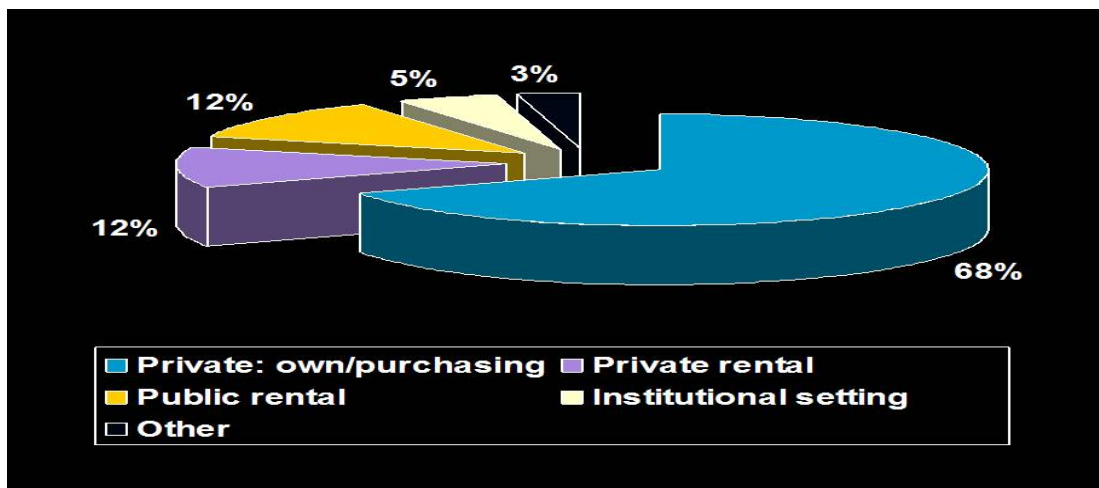
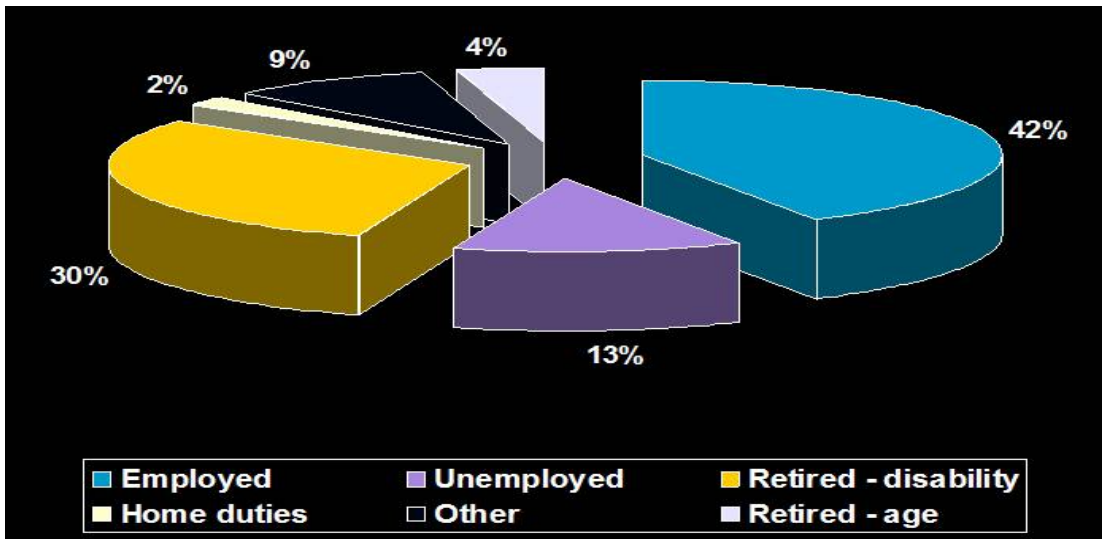


Figure 6 shows the breakdown of employment status across the sample. Clearly, the two largest groups are those 'employed' and those 'retired for disability'. It is worth noting that many of the participants, although reporting their status as 'employed', reported significant problems being associated with finding and maintaining appropriate levels of employment.

**Figure 6 Employment status breakdown**



**Functional / Clinical profile of the sample**

Figure 7 shows the average FIM score broken down by ‘motor’ score and ‘cognitive’ score by study cohort. The maximum scores possible with this instrument are 91 (motor), 35 cognition and therefore 126 (total). Interestingly, there is considerable consistency across both domains and across each of the cohorts with motor scores for the five year post injury cohort being less than the other cohorts.

**Figure 7 Average FIM scores by cohort**

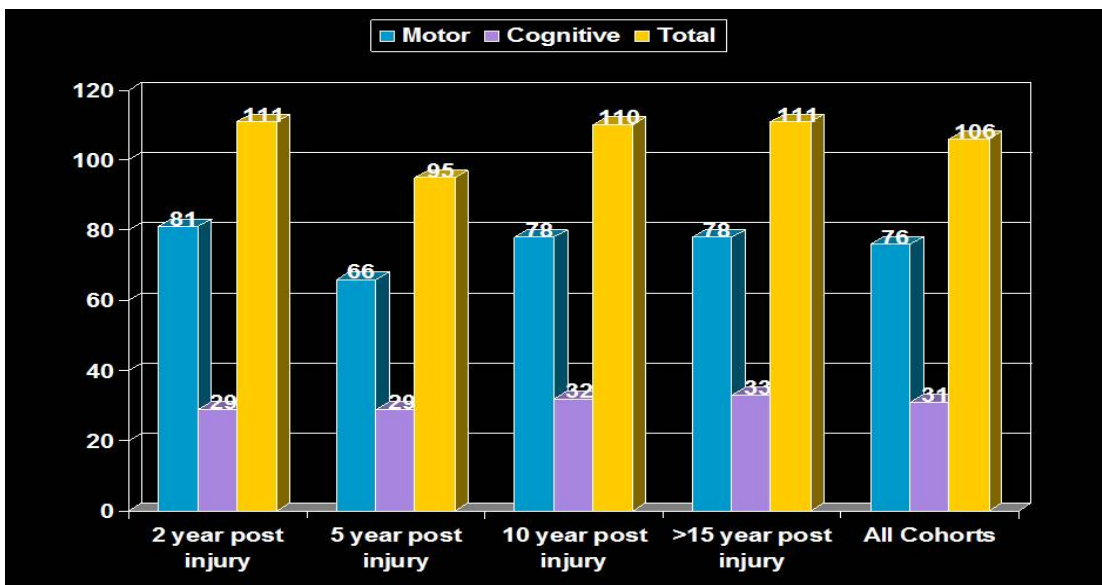


Figure 8 shows the CANS score for the TBI group. The CANS instrument is a relatively new instrument designed in Australia to measure the level of independence amongst individuals with a TBI. This thesis will offer one of the first opportunities to compare the results of the CANS instrument with some of the more established instruments such as the FIM and the SRS. A CANS score of eight indicates that a person requires full time supervision and cannot be left alone for even a few minutes. Approximately 8% of the sample were assigned this score.

Figure 8 CANS Score by cohort

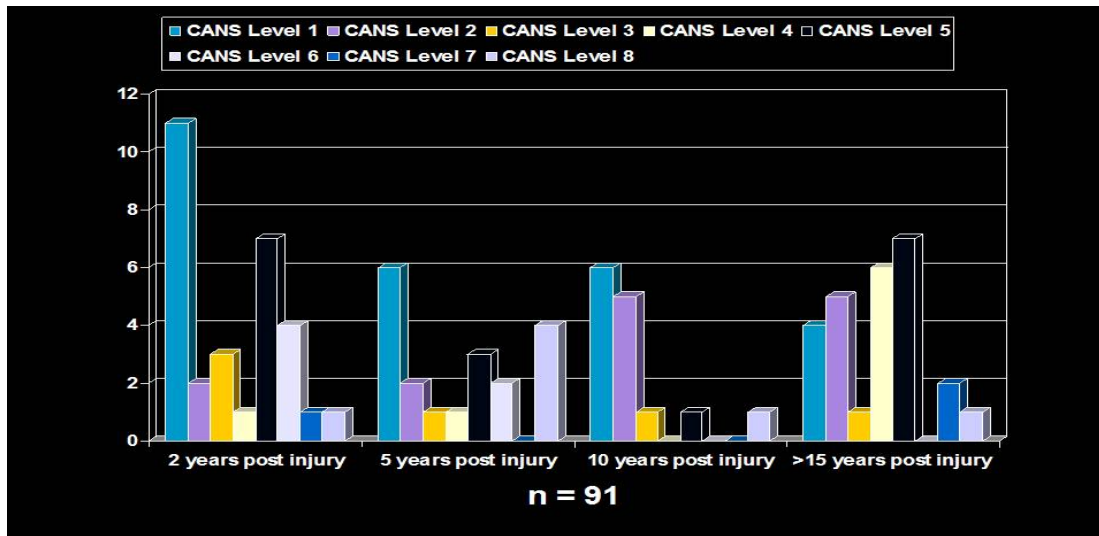
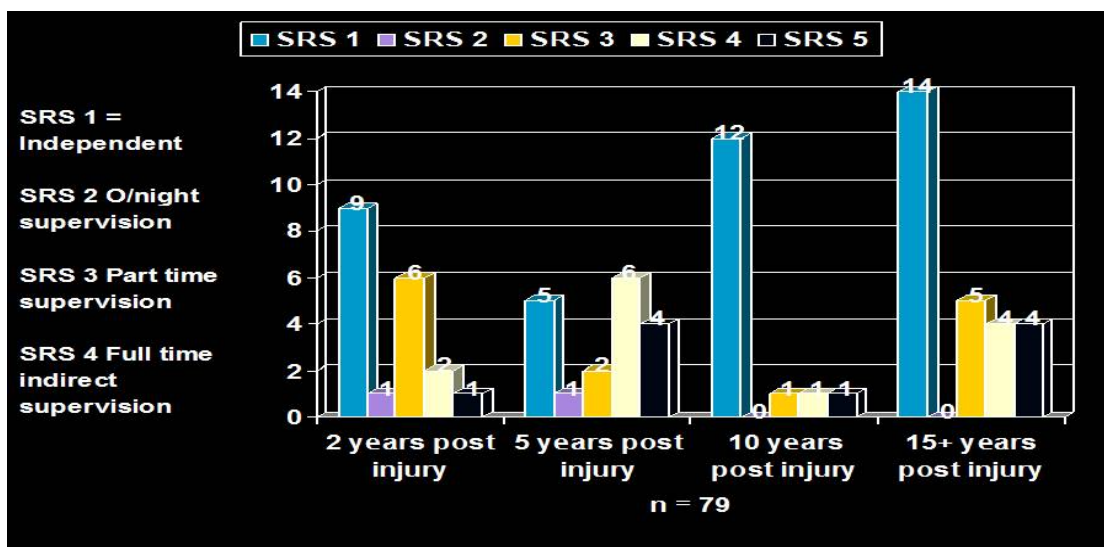


Figure 9 shows the SRS score for the TBI group. The proportion of patients assigned an SRS score of 5, indicating full time direct supervision is required was 12%.

Figure 9 Supervision Rating Scale by cohort



### Next steps

As noted, the next stage of the thesis will be to progress the data analysis and synthesise the overall results into a coherent set of findings that will be useful in the context of understanding the long term care needs and service utilisation patterns of this group. It is hoped that the results will prove particularly useful given the current policy debate regarding a national disability insurance scheme.

### Study Limitations

Two key limitations to the thesis are noted. Firstly, several of the study instruments rely on participants providing self-reported information. It is possible that participants have not provided accurate information either because of their level of disability or because of a lack of insight into their situation. Secondly, the sampling methodology,

whilst employing considerable rigour, has had to be balanced with the resource constraints of the study.

**Study timetable**

At the time of writing, all interviews have been completed. As noted, the data analysis is progressing and it is expected that the thesis will be submitted by mid 2012.

**Ethics approval**

Ethics approval was obtained from six relevant ethics committee's for the conduct of the thesis.

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