One and Five Year Outcomes After Moderate-to-Severe Traumatic Brain Injury Requiring Inpatient Rehabilitation

TRAUMATIC BRAIN INJURY REPORT

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EXECUTIVE SUMMARY

Traumatic brain injury (TBI) is an important public health concern in the United States. Surveys from two states suggest that 20-25% of adults have experienced at least one TBI with loss of consciousness sometime in their life.[1,2] Approximately 21,400 people aged 16 and over receive inpatient rehabilitation in the U.S. annually for moderate-to-severe TBI.[3,4] This report presents national outcome data about adolescents and adults who receive inpatient rehabilitation for a TBI. The estimates in the report are derived from individuals injured between 2001 and 2007 in the TBI Model System National Database which follows for a lifetime a large sample of people with moderate-to-severe TBI initially treated in inpatient rehabilitation. The TBI-related outcomes include a global measure of functional outcome, measures of cognitive and motor functioning, and a measure of the level of supervision the individual requires after their TBI.* These outcomes are assessed at 1 and 5 years after injury and are analyzed for demographic subgroups based on age and sex.

KEY GLOBAL FUNCTION FINDINGS

- An estimated 20% of individuals died within 5 years of injury, with higher mortality rates among older individuals.

- Sixty-one percent of individuals experienced a change in their global function between 1 and 5 years post-injury, with 26% improving and 35% declining or dying. With each increasing age category, both females and males experienced less improvement and more decline.

KEY COGNITIVE AND MOTOR FUNCTION AND SUPERVISION FINDINGS (Among Those Alive 5 Years Post-Injury)

- Almost half of individuals experienced a change in their cognitive function between 1 and 5 years post-injury, with 24% improving and 24% declining.

- One-third of individuals experienced change in their need for supervision between 1 and 5 years post-injury, with 17% needing less and 17% needing more.

- There was considerably less change in motor function, with 8% improving and 13% declining between 1 and 5 years post-injury.

- The pattern of improvement and decline is quite different in age subgroups, with people aged 16 to 49 showing better outcomes.

- Higher proportions of females age 70 and over experienced decline in cognitive and motor function than their male counterparts.

CONCLUSIONS

- Useful estimates of outcomes (and changes in outcomes) in the national population of adults receiving inpatient TBI rehabilitation can be derived from TBI Model System data.

- One-fifth of individuals who receive inpatient rehabilitation for moderate-to-severe TBI die within 5 years of their injury.

- For those who are alive 5 years after their injury, considerable change in function occurs over time after TBI, with improvement occurring about as frequently as decline between 1 and 5 years post-injury.

- Older age groups have more decline in all outcomes for both females and males.

HEALTH IMPLICATIONS

- Analysis of change over time within individuals highlights that TBI is a dynamic condition.

- The frequency and magnitude of change after TBI suggests the need for chronic disease management strategies including systematic prospective follow-up, interventions to prevent or slow decline in function, and access to continuing rehabilitation to respond to changing needs.

- Population-based trends in outcomes, analyzed by demographic subgroups (like those in this publication), may help in planning for the long-term needs of people who receive initial inpatient rehabilitation for TBI.

Note: * The specific instruments used to measure outcome are described in the next section "Report Methods and Charts."

REPORT METHODS AND CHARTS

The purpose of this report is to describe long-term functional outcomes after moderate-to-severe TBI. The population included in these analyses is people aged 16 and over who receive inpatient TBI rehabilitation after TBI in the United States. The time period covered is the first 5 years after injury, specifically outcomes at 1 year and 5 years after TBI, and changes in outcomes occurring between those two time points. The specific outcomes of interest include the following standardized instruments collected in interviews with individuals with TBI or their family members/caregivers:

GLOBAL FUNCTION

- The Glasgow Outcome Scale – Extended (GOS-E)[5] is an ordinal scale that measures global function. Patient status was classified into one of eight categories:

    1. Dead

    2. Vegetative State (only reflex responses)

    3. Lower Severe Disability (needs assistance and cannot be left alone for 8 hours)

    4. Upper Severe Disability (needs assistance but can be left alone for 8 hours)

    5. Lower Moderate Disability (independent at home but not able to return to work even with special arrangements)

    6. Upper Moderate Disability (independent at home and able to return to work with special arrangements)

    7. Lower Good Recovery (independent with the capacity to work, but minor disability)

    8. Upper Good Recovery (independent with the capacity to work and no disability)

LEVEL OF SUPERVISION

- The Supervision Rating Scale (SRS)[6] is an ordinal scale that measures the level of supervision that an individual receives from caregivers, grouped into three categories for this report: Independent (no supervision), Overnight/Part-Time Supervision, and Full-Time Supervision

COGNITIVE FUNCTION

- The Cognitive Subscale of the Functional Independence Measure (FIM)®[7] is a seven-level ordinal scale sed to rate the ability of individuals to perform independently in activities of daily living that includes the following 5 cognitive items:

    1. Comprehension

    2. Expression

    3. Social interaction

    4. Problem solving

    5. Memory

- Rating categories and associated scores are:
    1. Total Assistance (individual completes task without prompting less than 25% of the time)
    2. Maximal Assistance (individual completes task without prompting 25% to 49% of the time)
    3. Moderate Assistance (individual completes task without prompting 50 to 74% of the time)
    4. Minimal Assistance (individual completes task without prompting 75% to 90% of the time)
    5. Supervision (individual completes task without prompting more than 90% of the time)
    6. Modified Independence (individual requires use of a device or aid, but no prompting)
    7. Independence (no assistance or device)
- Scores in this report are averaged across the 5 items, rounded, and assigned the corresponding category

MOTOR FUNCTION

- The Motor Subscale of FIM®[7] is a seven-level ordinal scale used to rate the ability of individuals to perform independently in activities of daily living that includes the following 13 motor items:
    1. Eating
    2. Grooming
    3. Bathing
    4. Dressing, upper body
    5. Dressing, lower body
    6. Toileting
    7. Bladder management
    8. Bowel management
    9. Transfers - bed/chair/wheelchair
    10. Transfers - toilet
    11. Transfers - bath/shower
    12. Walk/wheelchair
    13. Stairs
- Rating categories and associated scores are:
    1. Total Assistance (individual can perform less than 25% of the task or requires more than one person to assist)
    2. Maximal Assistance (individual can perform 25% to 49% of task)
    3. Moderate Assistance (individual can perform 50% to 74% of task)
    4. Minimal Assistance (individual can perform 75% or more of task)
    5. Supervision (supervision or set-up only)
    6. Modified Independence (patient requires use of a device or aid, but no physical assistance)
    7. Independence (no assistance or device)
- Scores in this report are averaged across the 13 items, rounded, and assigned the corresponding category

Data used in preparing this report came from two sources. Information about the **number and characteristics** of people receiving inpatient TBI rehabilitation in the U.S. are collected by the Uniform Data System for Medical Rehabilitation and the American Medical Rehabilitation Providers Association's eRehabData, which together gather data on all inpatients seen in over 90% of the rehabilitation facilities in the U.S. Information about the **characteristics and long-term outcomes** of people receiving inpatient TBI rehabilitation are collected by 20 federally designated TBI Model Systems (TBIMS) around the U.S., which enroll a large sample of cases in the TBIMS National Database (NDB) and follow them at 1, 2, and 5 years after injury (and every 5 years thereafter) and assesses a range of patient outcomes. Individuals aged 16 and over who received inpatient TBI rehabilitation between Oct 1, 2001 and Dec 31, 2007 were selected from these datasets for analysis. The 4,788 patients from the TBIMS NDB were followed for five years and were weighted to represent the 99,339 patients in the national population. The sophisticated procedures used to weight the TBIMS cases are detailed in the Methodological Appendix. These procedures allowed the known 1 and 5 year outcomes of the TBIMS cases to be used to estimate outcomes for all individuals in the U.S. receiving inpatient TBI rehabilitation. These best estimates of outcomes after inpatient TBI rehabilitation in the U.S. are presented in this report using 5 charts per outcome:

- **Chart 1:** Labeled *Distribution of [Outcome] at 1 and 5 Years Post-Injury*, this chart shows the proportion of each category within an outcome for the population at one year (in the left column) and five years (in the right column)

- **Chart 2:** Labeled *Change in [Outcome] from Year 1 to Year 5 Post-Injury*, this chart shows the proportion of people in the population who improved or declined from one category to another

- **Charts 3 and 4:** Labeled *Distribution of [Outcome]: for Females/Males at 1 and 5 Years Post-Injury*, these charts show the same information as Chart 1 but stratify outcomes by the sex of the patient. On their respective charts, female and male individuals are further divided into age groups at injury: 16-29, 30-49, 50-69, and 70+

- **Chart 5:** Labeled *Change in [Outcome] by Sex and Age from Year 1 to Year 5 Post-Injury*, this chart shows the same information as Chart 2 divided into sex and age subgroups in the same manner as Chart 3

Note that the charts for global function include all individuals, whether they survived or not. However, charts for supervision and cognitive and motor function are limited to those individuals who survived to at least their 5th anniversary of injury. By limiting both the 1 and 5 year data to 5 year survivors, the same cases are included at both time points, making the comparisons more valid.

GLOBAL FUNCTION

DISTRIBUTION OF GLOBAL FUNCTION CATEGORIES AT 1 AND 5 YEARS AFTER MODERATE-TO-SEVERE TBI*

DISTRIBUTION	YEAR 1	YEAR 5
Upper Good Recovery	25.1%	26.1%
Lower Good Recovery	13.2%	8.8%
Upper Moderate Disability	13.3%	11.1%
Lower Moderate Disability	8.9%	6.5%
Upper Severe Disability	15.4%	10.3%
Lower Severe Disability	17.8%	16.8%
Vegetative State	0.3%	0.4%
Dead	6.1%	20.0%
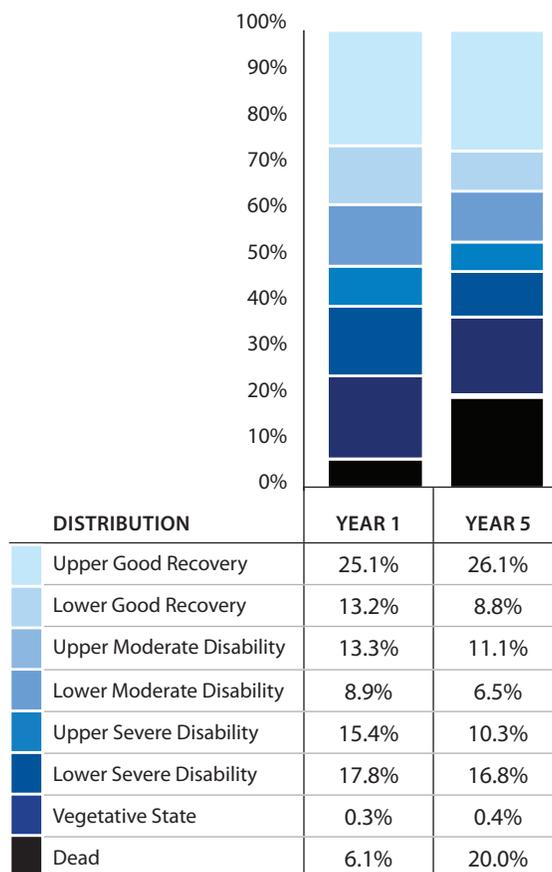
This chart depicts the comparison of Year 1 and Year 5 global function category frequencies for the population. The bar on the left indicates that 25.1% of individuals were in the Upper Good Recovery category at 1 year post-injury, while 6.1% had died. As shown in the bar on the right, a similar proportion (26.1%) were in the top recovery category at 5 years post-injury, but 20.0% had died in the first 5 years after injury.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.

CHANGE IN GLOBAL FUNCTION FROM YEAR 1 TO YEAR 5 AFTER MODERATE-TO-SEVERE TBI*

DISTRIBUTION	CHANGE YEAR 1 TO 5
Improved 4+ Categories	2.1%
Improved 2-3 Categories	10.4%
Improved 1 Category	13.4%
No Category Change	39.0%
Declined 1 Category	11.8%
Declined 2-3 Categories	14.1%
Declined 4+ Categories	9.1%
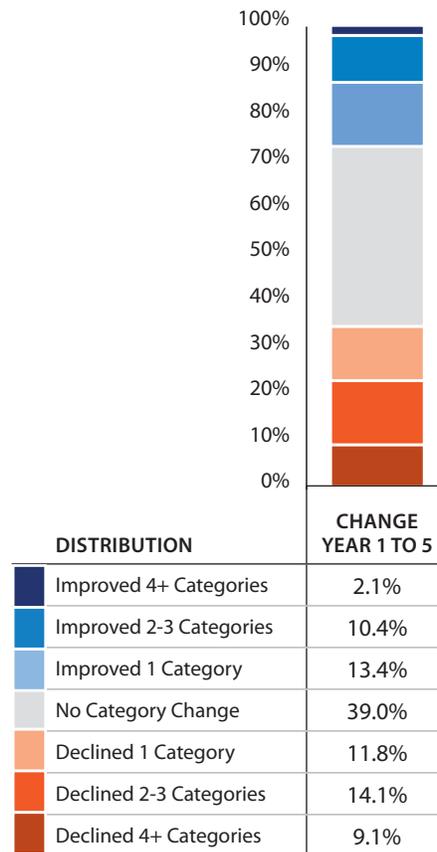
This chart depicts the proportion of the population that improved or declined from Year 1 to Year 5 in global function. Between years 1 and 5, 39.0% of individuals experienced no change in GOS-E category. Slightly more individuals declined 1 to 3 categories (25.9%) than improved 1 to 3 categories (23.8%). The proportion of individuals who declined 4 or more categories (9.1%) was more than 4 times greater than the proportion who improved 4 or more categories (2.1%).

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.

DISTRIBUTION OF GLOBAL FUNCTION FOR FEMALES BY AGE AT 1 AND 5 YEARS AFTER MODERATE-TO-SEVERE TBI*

DISTRIBUTION	FEMALE 16 - 29 YEAR 1	FEMALE 16 - 29 YEAR 5	FEMALE 30 - 49 YEAR 1	FEMALE 30 - 49 YEAR 5	FEMALE 50 - 69 YEAR 1	FEMALE 50 - 69 YEAR 5	FEMALE 70+ YEAR 1	FEMALE 70+ YEAR 5
Upper Good Recovery	29.9%	45.4%	17.5%	23.0%	23.3%	26.8%	21.4%	20.1%
Lower Good Recovery	17.7%	15.8%	13.1%	5.7%	14.7%	9.6%	14.4%	4.9%
Upper Moderate Disability	20.3%	18.4%	24.5%	33.5%	11.3%	8.5%	2.3%	1.7%
Lower Moderate Disability	8.3%	6.6%	11.7%	12.7%	8.4%	8.2%	6.1%	0.0%
Upper Severe Disability	13.6%	4.0%	16.4%	8.0%	15.9%	9.1%	21.0%	19.9%
Lower Severe Disability	8.7%	7.8%	13.4%	7.5%	22.0%	21.6%	26.5%	25.1%
Vegetative State	1.5%	.9%	.2%	0.0%	0.0%	0.0%	0.0%	0.0%
Dead	.1%	1.2%	3.2%	9.5%	4.5%	16.3%	8.2%	28.2%

This chart depicts the comparison of Year 1 and Year 5 global function for the female population by age subgroups. Lighter shades of blue represent better outcomes than darker shades of blue; black shading represents death.

Improvement was demonstrated by a higher proportion of the youngest age females (16-29) compared to older age females. At Year 5, the highest proportion of Upper Good Recovery is among females age 16-29 (45.4%). At Year 5, the highest rate of death is 28.2% among females age 70 and over.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
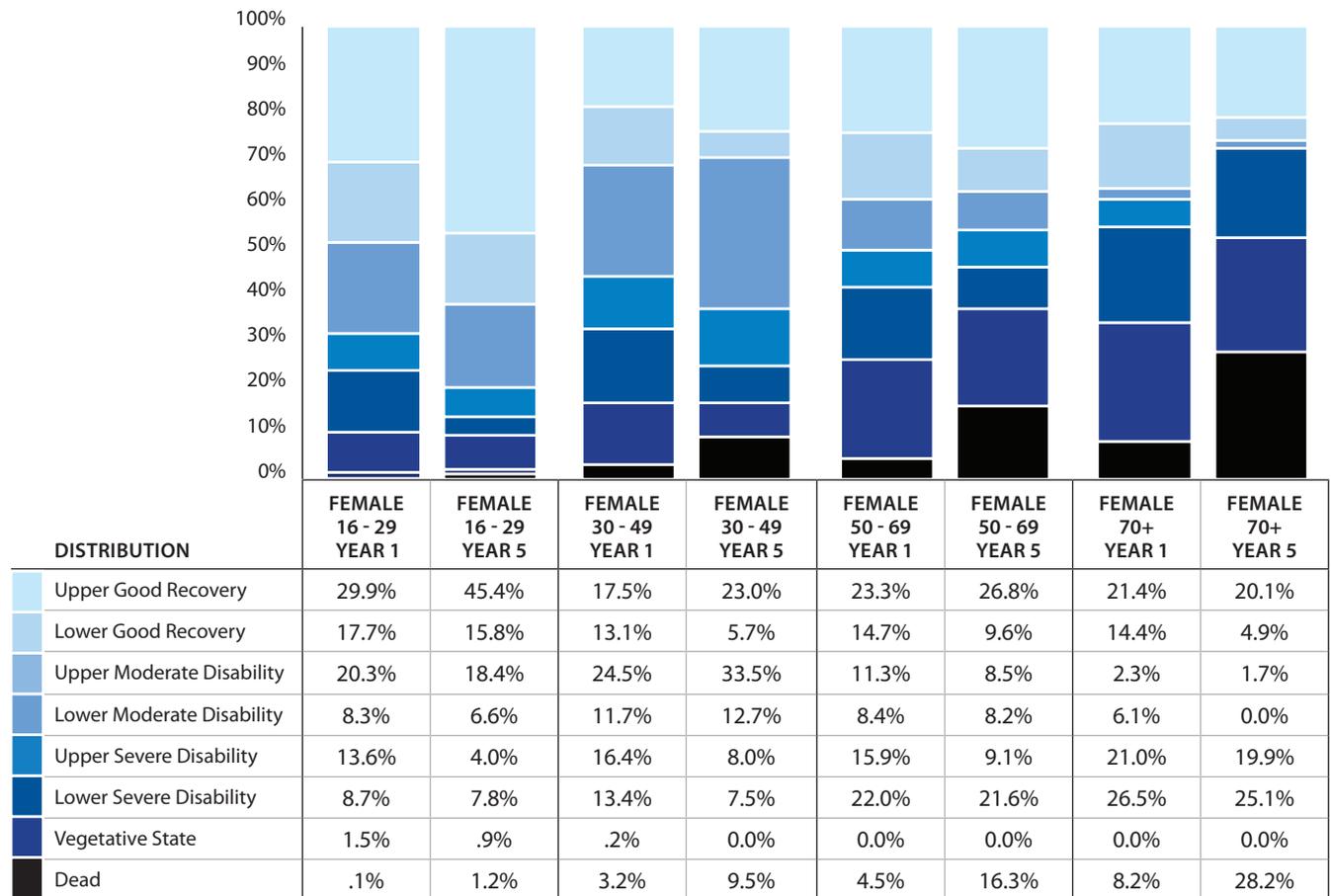
DISTRIBUTION OF GLOBAL FUNCTION FOR MALES BY AGE AT 1 AND 5 YEARS AFTER MODERATE-TO-SEVERE TBI*
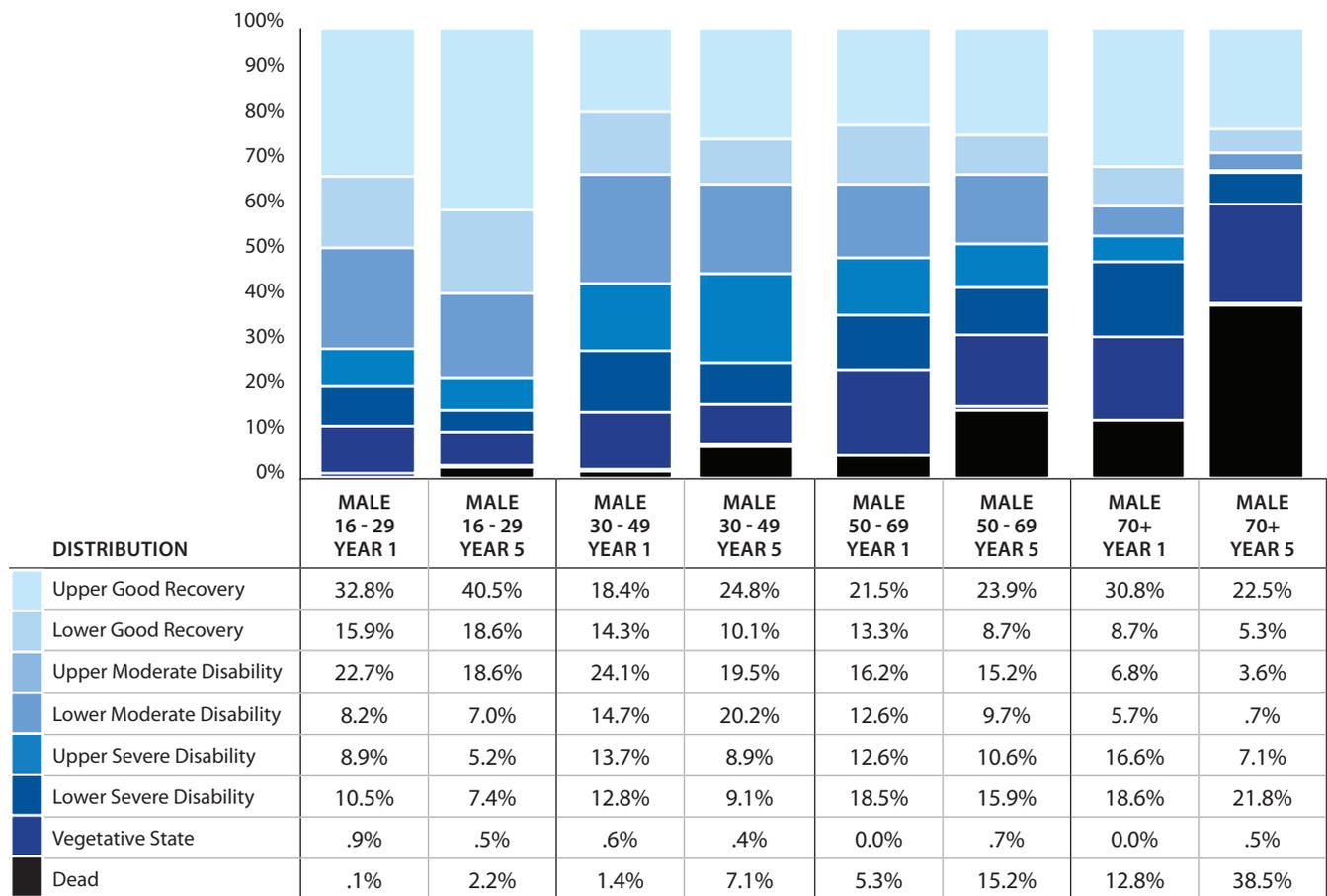

DISTRIBUTION	MALE 16 - 29 YEAR 1	MALE 16 - 29 YEAR 5	MALE 30 - 49 YEAR 1	MALE 30 - 49 YEAR 5	MALE 50 - 69 YEAR 1	MALE 50 - 69 YEAR 5	MALE 70+ YEAR 1	MALE 70+ YEAR 5
Upper Good Recovery	32.8%	40.5%	18.4%	24.8%	21.5%	23.9%	30.8%	22.5%
Lower Good Recovery	15.9%	18.6%	14.3%	10.1%	13.3%	8.7%	8.7%	5.3%
Upper Moderate Disability	22.7%	18.6%	24.1%	19.5%	16.2%	15.2%	6.8%	3.6%
Lower Moderate Disability	8.2%	7.0%	14.7%	20.2%	12.6%	9.7%	5.7%	.7%
Upper Severe Disability	8.9%	5.2%	13.7%	8.9%	12.6%	10.6%	16.6%	7.1%
Lower Severe Disability	10.5%	7.4%	12.8%	9.1%	18.5%	15.9%	18.6%	21.8%
Vegetative State	.9%	.5%	.6%	.4%	0.0%	.7%	0.0%	.5%
Dead	.1%	2.2%	1.4%	7.1%	5.3%	15.2%	12.8%	38.5%

This chart depicts the comparison of Year 1 and Year 5 global function in the male population by age subgroups. Lighter shades of blue represent better outcomes than darker shades of blue; black shading represents death.

As with females, improvement was demonstrated by a higher proportion of the youngest age males (16-29) compared to older age males. At Year 5, the highest proportion of Upper Good Recovery is among males age 16-29 (40.5%). At Year 5, the highest rate of death is 38.5% among males age 70 and over.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.

CHANGE IN GLOBAL FUNCTION BY SEX AND AGE FROM YEAR 1 TO YEAR 5 AFTER MODERATE-TO-SEVERE TBI*

DISTRIBUTION	FEMALE 16-29 YR 1 TO 5	FEMALE 30-49 YR 1 TO 5	FEMALE 50-69 YR 1 TO 5	FEMALE 70+ YR 1 TO 5	MALE 16-29 YR 1 TO 5	MALE 30-49 YR 1 TO 5	MALE 50-69 YR 1 TO 5	MALE 70+ YR 1 TO 5
Improved 4+ Categories	3.1%	1.6%	3.0%	3.7%	2.2%	1.4%	2.0%	.6%
Improved 2-3 Categories	18.4%	15.7%	11.5%	6.1%	17.7%	13.5%	10.7%	5.5%
Improved 1 Category	20.7%	20.3%	16.7%	10.6%	20.7%	19.2%	12.0%	6.0%
No Category Change	41.1%	40.9%	39.4%	35.4%	37.2%	39.2%	44.5%	38.9%
Declined 1 Category	11.4%	9.7%	6.7%	9.6%	14.2%	13.7%	13.2%	12.2%
Declined 2-3 Categories	4.9%	7.3%	13.9%	16.2%	6.5%	8.8%	10.7%	24.7%
Declined 4+ Categories	.4%	4.5%	8.8%	18.4%	1.5%	4.1%	6.9%	12.1%

This chart depicts the proportion of the population who improved or declined in global function from Year 1 to Year 5, divided into sex and age subgroups. With each increasing age category, both females and males experienced less improvement and more decline in global function. Males age 70 and over experienced the greatest decline, with 12.2% declining 1 category and 36.8% declining 2 or more categories. Similarly, 9.6% of females age 70 and over saw a 1 category decline, with 34.6% declining 2 or more categories.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.

LEVEL OF SUPERVISION

DISTRIBUTION OF SUPERVISION AT 1 AND 5 YEARS POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	YEAR 1	YEAR 5
Independent	55.7%	57.6%
Overnight/PT Supervision	32.2%	27.1%
FT Supervision	12.1%	15.3%
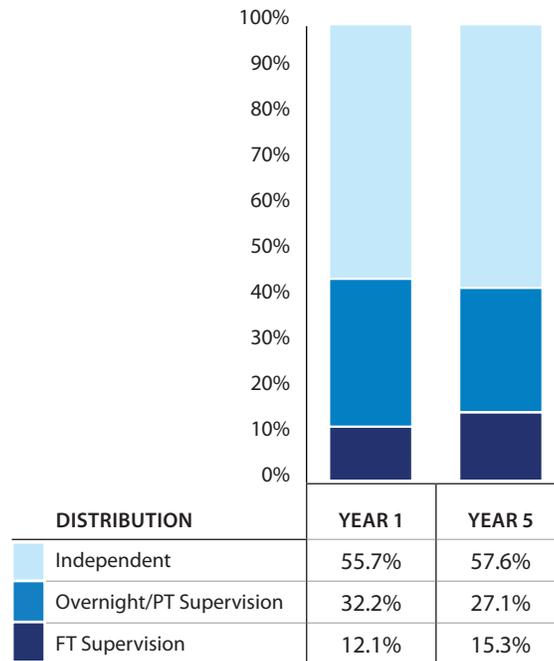
This chart depicts the comparison of level of supervision at Year 1 and Year 5 in the population (alive at 5 years post-injury). The bar on the left indicates that 55.7% of individuals were in the independent category at 1 year post-injury, while 12.1% needed full-time (FT) supervision. As shown in the bar on the right, there was a slight increase in the proportion of individuals classified as independent (57.6%) at 5 years post-injury, as well as an increase in those requiring FT supervision (15.3%) but a decrease in those requiring overnight or part-time supervision (from 32.2% to 27.1%).

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.

CHANGE IN SUPERVISION FROM YEAR 1 TO YEAR 5 POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	CHANGE YEAR 1 TO 5
Improved 2 Categories	0.9%
Improved 1 Category	16.4%
No Category Change	65.6%
Declined 1 Category	14.3%
Declined 2 Categories	2.8%

This chart depicts the proportion of the population (alive at 5 years post-injury) that improved or declined change in their need for supervision from Year 1 to Year 5. Between years 1 and 5, the majority of individuals (65.6%) experienced no change in the need for supervision. Slightly more individuals improved 1 category (16.4%) than declined 1 category (14.3%), yet 2.8% of individuals declined 2 categories, whereas only 0.9% improved 2 categories.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
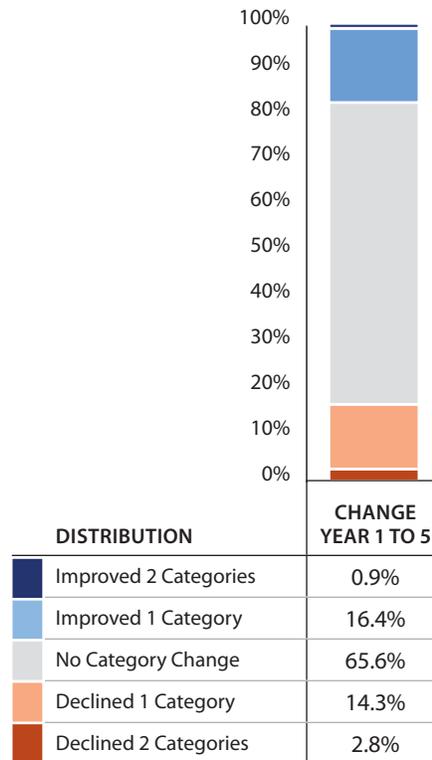
DISTRIBUTION OF SUPERVISION FOR FEMALES BY AGE AT 1 AND 5 YEARS POST-INJURY AMONG 5-YEAR SURVIVORS*

DISTRIBUTION	FEMALE 16 - 29 YEAR 1	FEMALE 16 - 29 YEAR 5	FEMALE 30 - 49 YEAR 1	FEMALE 30 - 49 YEAR 5	FEMALE 50 - 69 YEAR 1	FEMALE 50 - 69 YEAR 5	FEMALE 70+ YEAR 1	FEMALE 70+ YEAR 5
Independent	57.7%	77.9%	58.5%	74.0%	45.4%	53.7%	44.6%	32.5%
Overnight/PT Supervision	36.4%	18.3%	34.6%	20.9%	38.8%	26.2%	38.3%	40.1%
FT Supervision	5.9%	3.8%	6.9%	5.1%	15.8%	20.1%	17.1%	27.4%

This chart depicts the comparison of need for supervision at Year 1 and Year 5 in the female population (alive at 5 years post-injury), divided into age subgroups. Lighter colors indicate better outcomes than darker ones. As illustrated by the color patterns, younger females were more independent than older females. The highest proportion of independent females was age 16-29 at Year 5 (77.9%), followed by females at age 30-49, also at Year 5 (74.0%).

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
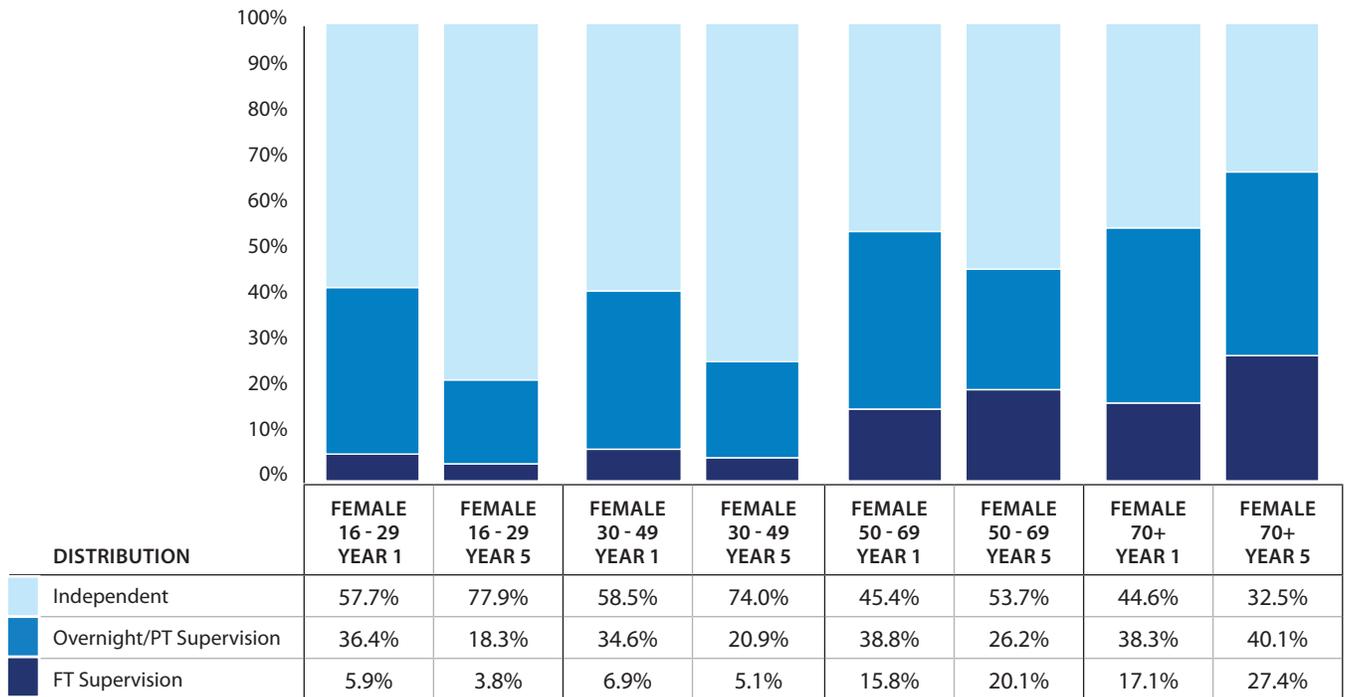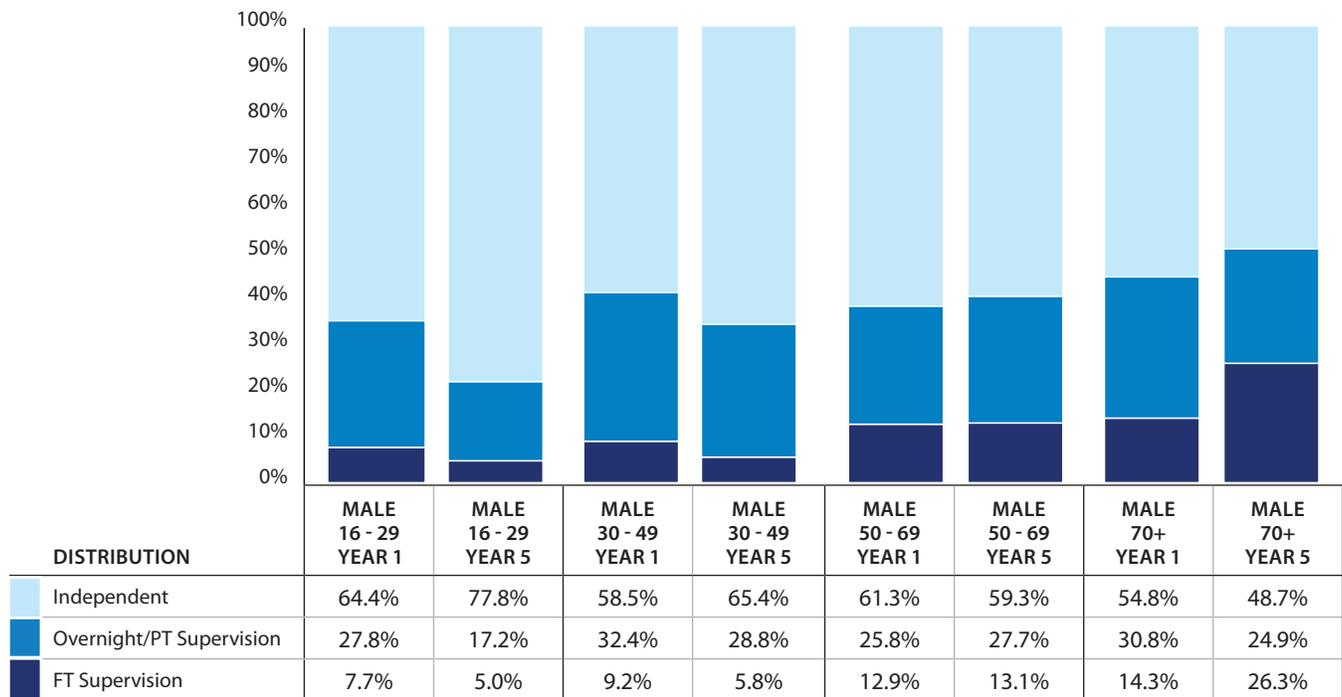
DISTRIBUTION OF SUPERVISION FOR MALES BY AGE AT 1 AND 5 YEARS POST-INJURY AMONG 5-YEAR SURVIVORS*

DISTRIBUTION	MALE 16 - 29 YEAR 1	MALE 16 - 29 YEAR 5	MALE 30 - 49 YEAR 1	MALE 30 - 49 YEAR 5	MALE 50 - 69 YEAR 1	MALE 50 - 69 YEAR 5	MALE 70+ YEAR 1	MALE 70+ YEAR 5
Independent	64.4%	77.8%	58.5%	65.4%	61.3%	59.3%	54.8%	48.7%
Overnight/PT Supervision	27.8%	17.2%	32.4%	28.8%	25.8%	27.7%	30.8%	24.9%
FT Supervision	7.7%	5.0%	9.2%	5.8%	12.9%	13.1%	14.3%	26.3%

This chart depicts the comparison of need for supervision at Year 1 and Year 5 in the male population (alive at 5 years post-injury), divided into age subgroups. Lighter colors indicate better outcomes than darker ones. As illustrated by the color patterns, younger males were more independent than older males. The highest proportion of independent males was age 16-29 at Year 5 (77.8%). In general, the proportion of independent males was equal to or greater than the proportion of independent females at 1 and 5 years post-injury across all age groups except for age 30-49 at 5 years post-injury; a lower proportion of males were independent (65.4%) than females (74.0%).

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
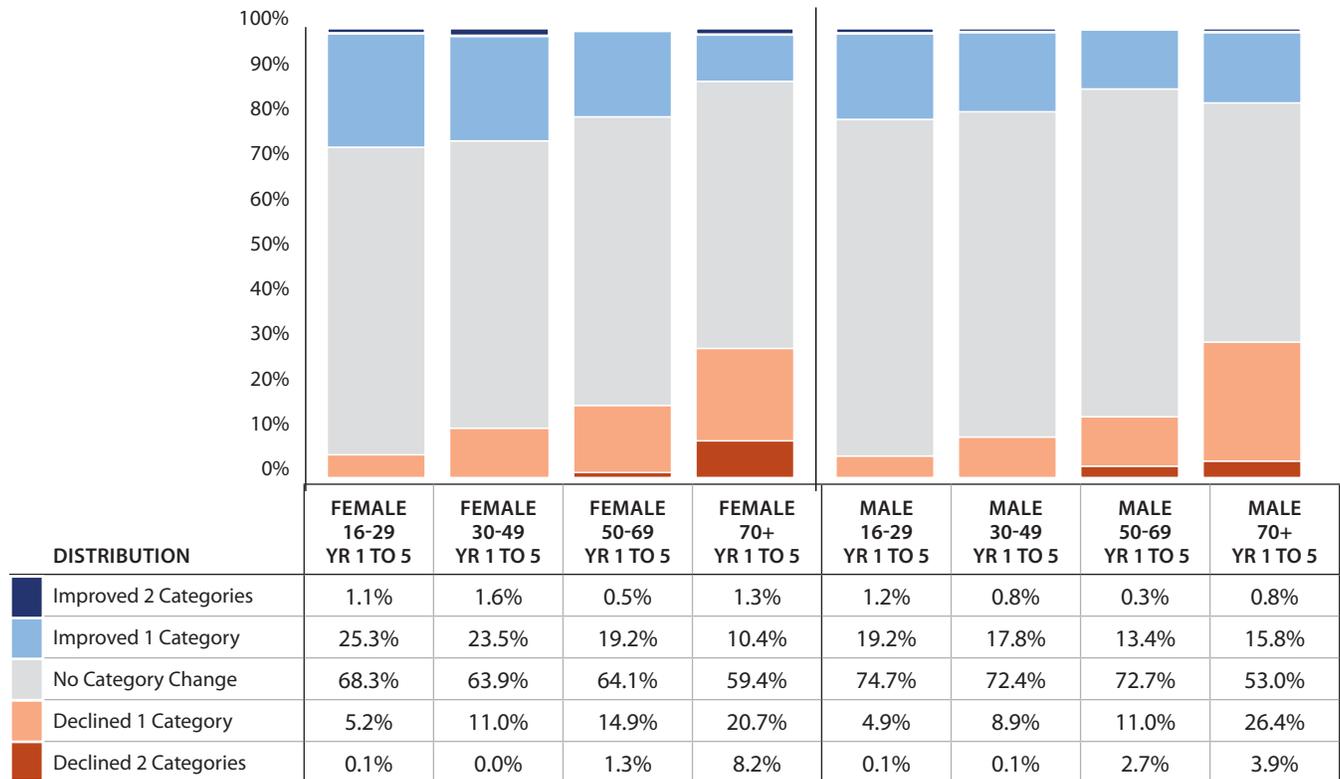
CHANGE IN SUPERVISION BY SEX AND AGE FROM YEAR 1 TO YEAR 5 POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

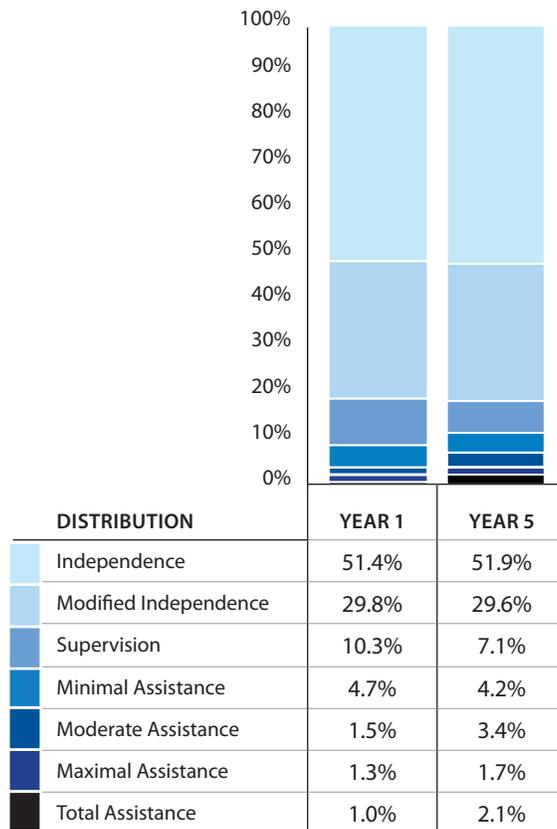| DISTRIBUTION	FEMALE 16-29 YR 1 TO 5	FEMALE 30-49 YR 1 TO 5	FEMALE 50-69 YR 1 TO 5	FEMALE 70+ YR 1 TO 5	MALE 16-29 YR 1 TO 5	MALE 30-49 YR 1 TO 5	MALE 50-69 YR 1 TO 5	MALE 70+ YR 1 TO 5
Improved 2 Categories	1.1%	1.6%	0.5%	1.3%	1.2%	0.8%	0.3%	0.8%
Improved 1 Category	25.3%	23.5%	19.2%	10.4%	19.2%	17.8%	13.4%	15.8%
No Category Change	68.3%	63.9%	64.1%	59.4%	74.7%	72.4%	72.7%	53.0%
Declined 1 Category	5.2%	11.0%	14.9%	20.7%	4.9%	8.9%	11.0%	26.4%
Declined 2 Categories	0.1%	0.0%	1.3%	8.2%	0.1%	0.1%	2.7%	3.9%

This chart depicts the proportion of the population (alive at 5 years post-injury) that improved or declined in supervision requirements from Year 1 to Year 5, divided into sex and age subgroups. Over 60% of females younger than age 70 experienced no change in supervision requirements, and over 70% of males under the age of 70 experienced no change. However, as the graph colors illustrate, among those who did experience a change, older age groups saw more decline than younger ones for both males and females.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
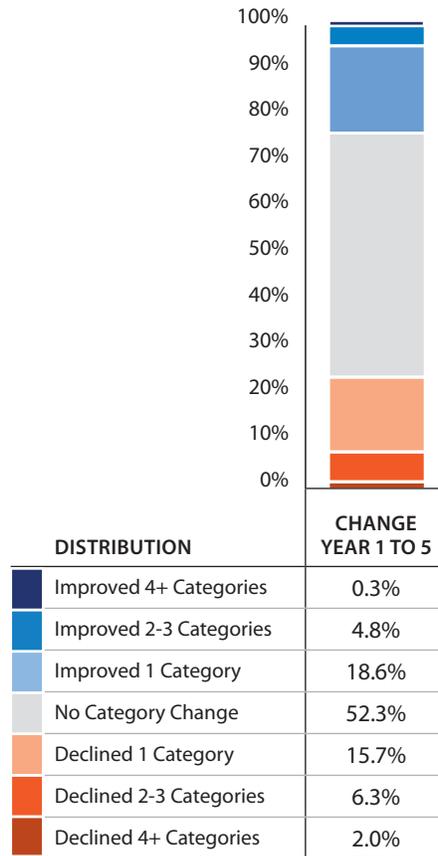
COGNITIVE FUNCTION

DISTRIBUTION OF COGNITIVE FUNCTION AT 1 AND 5 YEARS POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	YEAR 1	YEAR 5
Independence	51.4%	51.9%
Modified Independence	29.8%	29.6%
Supervision	10.3%	7.1%
Minimal Assistance	4.7%	4.2%
Moderate Assistance	1.5%	3.4%
Maximal Assistance	1.3%	1.7%
Total Assistance	1.0%	2.1%

This chart depicts the comparison of Year 1 and Year 5 cognitive function in the population (alive at 5 years post-injury). The bar on the left indicates that 81.2% of individuals were either independent (51.4%) or had modified independence (29.8%) at 1 year post-injury, with 8.5% needing assistance beyond supervision. As shown in the bar on the right, at Year 5 there was virtually no change in the proportion of individuals who were independent (51.9%) or had modified independence (29.6%), with a slightly larger proportion (11.4%) needing assistance.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.

CHANGE IN COGNITIVE FUNCTION FROM YEAR 1 TO YEAR 5 POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	CHANGE YEAR 1 TO 5
Improved 4+ Categories	0.3%
Improved 2-3 Categories	4.8%
Improved 1 Category	18.6%
No Category Change	52.3%
Declined 1 Category	15.7%
Declined 2-3 Categories	6.3%
Declined 4+ Categories	2.0%

This chart depicts the proportion of the population (alive at 5 years post-injury) that improved or declined categories from Year 1 to Year 5 in cognitive function. Between years 1 and 5, nearly half of all individuals (47.7%) experienced change in cognitive function. Slightly more individuals improved 1 category (18.6%) than declined 1 category (15.7%), yet slightly fewer individuals improved 2 or more categories (5.1%) than declined 2 or more categories. Overall, individuals who experienced a change in cognitive function were almost equally split between improvement (23.7%) and decline (24.0%).

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
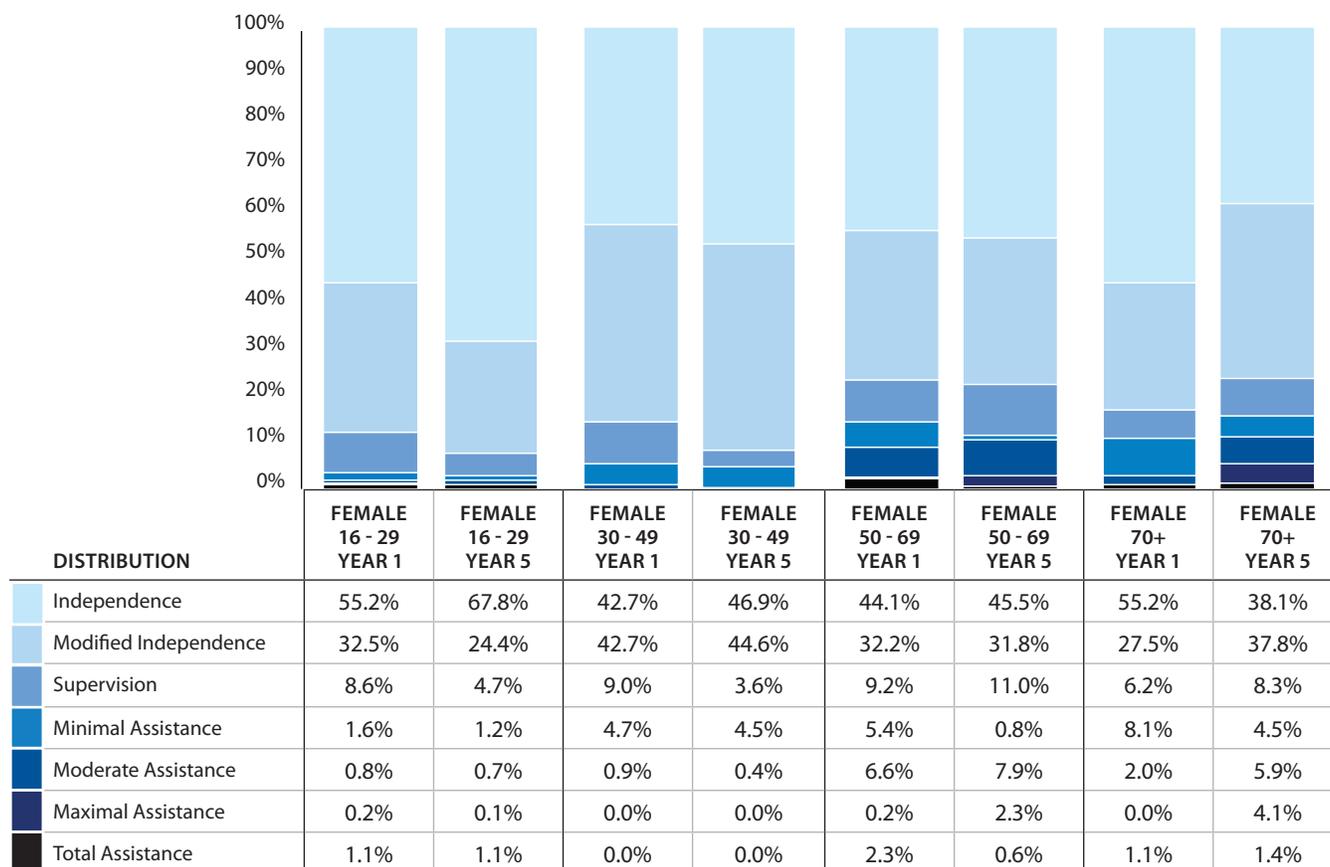
DISTRIBUTION OF COGNITIVE FUNCTION FOR FEMALES BY AGE AT 1 AND 5 YEARS POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	FEMALE 16 - 29 YEAR 1	FEMALE 16 - 29 YEAR 5	FEMALE 30 - 49 YEAR 1	FEMALE 30 - 49 YEAR 5	FEMALE 50 - 69 YEAR 1	FEMALE 50 - 69 YEAR 5	FEMALE 70+ YEAR 1	FEMALE 70+ YEAR 5
Independence	55.2%	67.8%	42.7%	46.9%	44.1%	45.5%	55.2%	38.1%
Modified Independence	32.5%	24.4%	42.7%	44.6%	32.2%	31.8%	27.5%	37.8%
Supervision	8.6%	4.7%	9.0%	3.6%	9.2%	11.0%	6.2%	8.3%
Minimal Assistance	1.6%	1.2%	4.7%	4.5%	5.4%	0.8%	8.1%	4.5%
Moderate Assistance	0.8%	0.7%	0.9%	0.4%	6.6%	7.9%	2.0%	5.9%
Maximal Assistance	0.2%	0.1%	0.0%	0.0%	0.2%	2.3%	0.0%	4.1%
Total Assistance	1.1%	1.1%	0.0%	0.0%	2.3%	0.6%	1.1%	1.4%

This chart depicts the comparison of Year 1 and Year 5 cognitive function in the female population (alive at 5 years post-injury), divided into age subgroups. Lighter colors indicate better outcomes than darker ones. As illustrated by the color patterns, most females were independent or had modified independence regardless of age or year post-injury. The proportion requiring assistance was higher among females age 50 and over.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
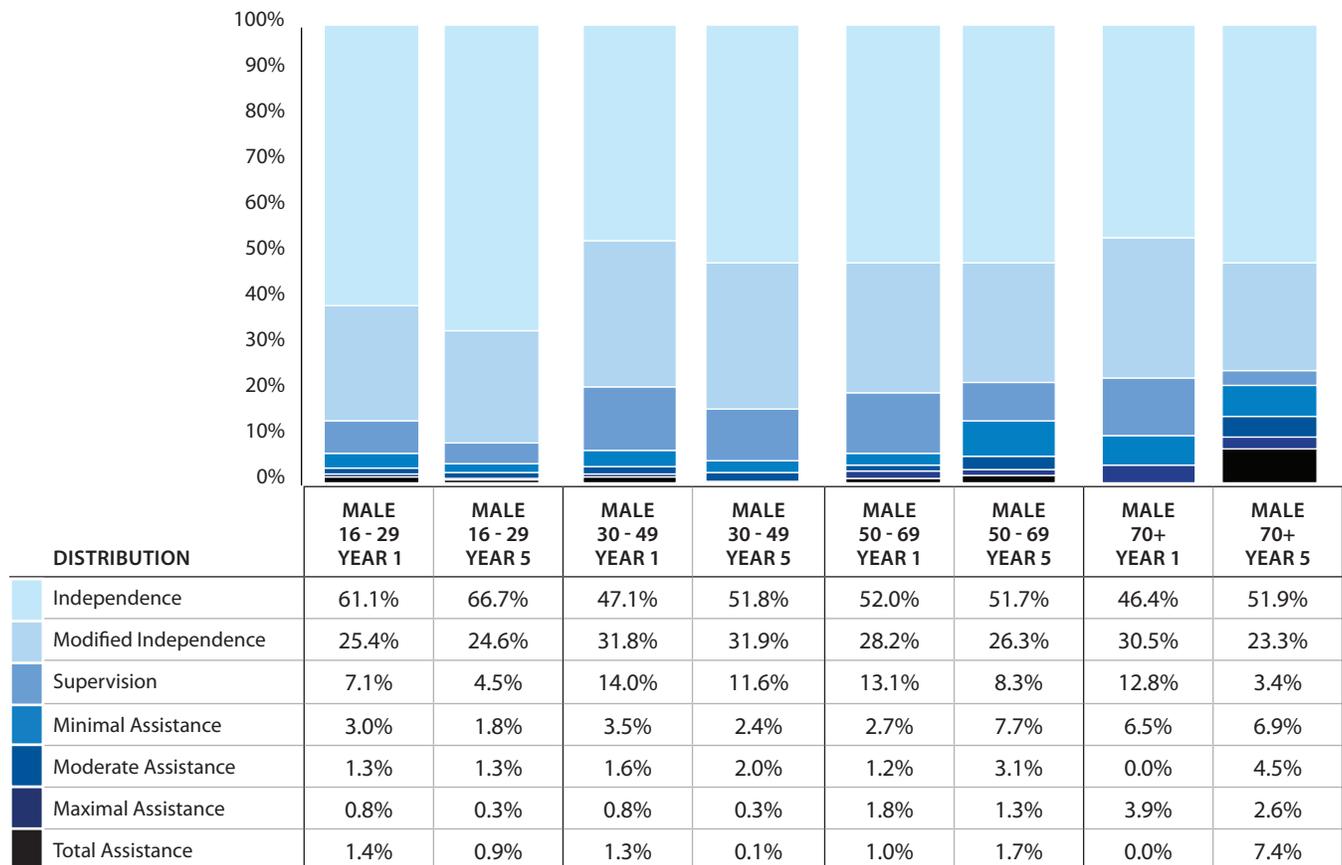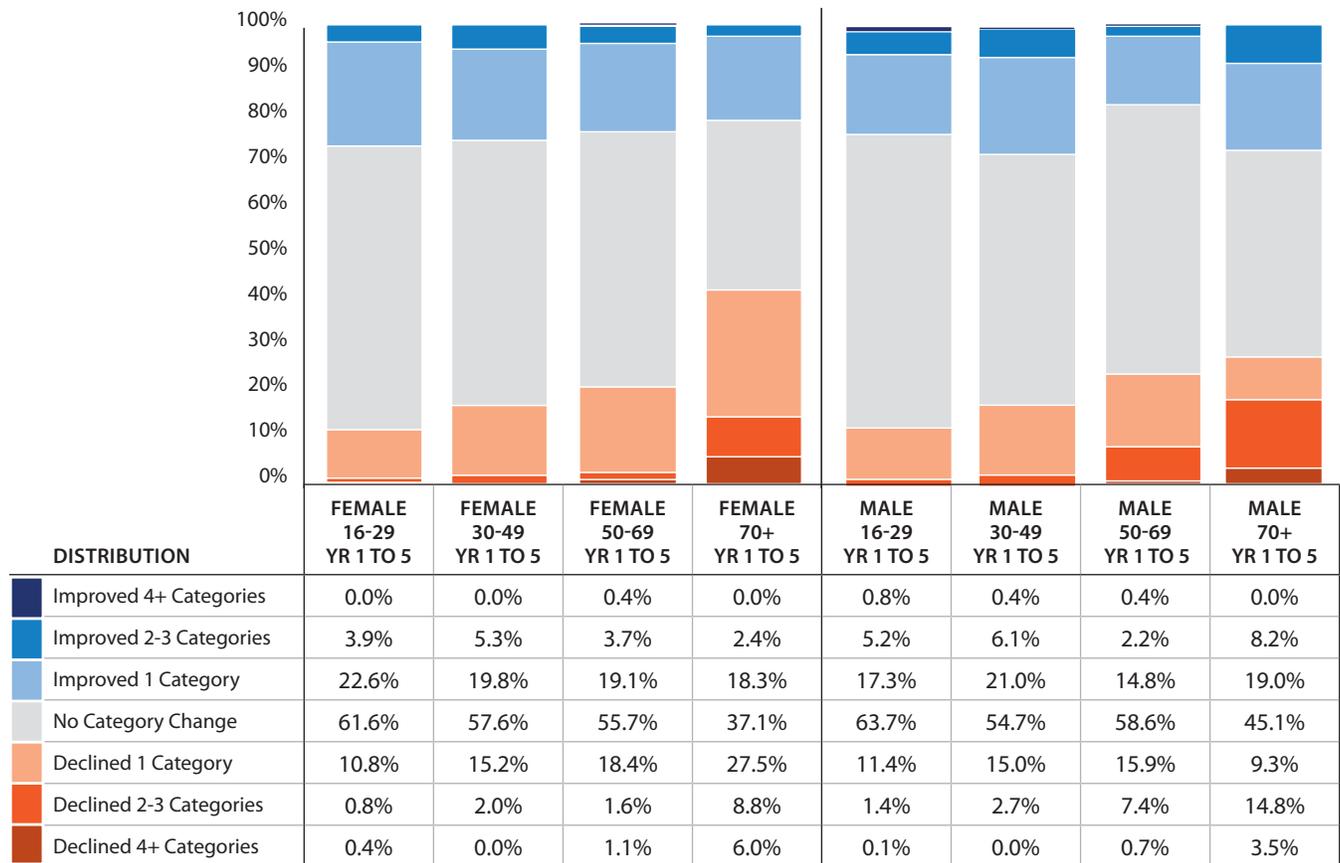
DISTRIBUTION OF COGNITIVE FUNCTION FOR MALES BY AGE AT 1 AND 5 YEARS POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	MALE 16 - 29 YEAR 1	MALE 16 - 29 YEAR 5	MALE 30 - 49 YEAR 1	MALE 30 - 49 YEAR 5	MALE 50 - 69 YEAR 1	MALE 50 - 69 YEAR 5	MALE 70+ YEAR 1	MALE 70+ YEAR 5
Independence	61.1%	66.7%	47.1%	51.8%	52.0%	51.7%	46.4%	51.9%
Modified Independence	25.4%	24.6%	31.8%	31.9%	28.2%	26.3%	30.5%	23.3%
Supervision	7.1%	4.5%	14.0%	11.6%	13.1%	8.3%	12.8%	3.4%
Minimal Assistance	3.0%	1.8%	3.5%	2.4%	2.7%	7.7%	6.5%	6.9%
Moderate Assistance	1.3%	1.3%	1.6%	2.0%	1.2%	3.1%	0.0%	4.5%
Maximal Assistance	0.8%	0.3%	0.8%	0.3%	1.8%	1.3%	3.9%	2.6%
Total Assistance	1.4%	0.9%	1.3%	0.1%	1.0%	1.7%	0.0%	7.4%

This chart depicts the comparison of Year 1 and Year 5 cognitive function in the male population (alive at 5 years post-injury), divided into age subgroups. Lighter colors indicate better outcomes than darker ones. As illustrated by the color patterns, most males were independent or had modified independence regardless of age or year post-injury. The proportion of males requiring supervision or assistance was lower among males under age 30.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.

CHANGE IN COGNITIVE FUNCTION BY SEX AND AGE FROM 1 TO 5 YEARS POSTINJURY AMONG 5-YEAR SURVIVORS OF POST-INJURY TBI*

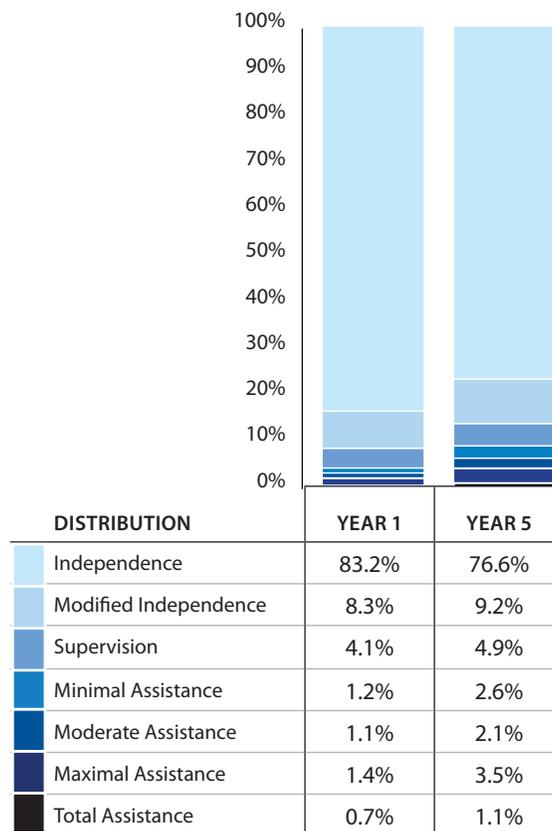| DISTRIBUTION	FEMALE 16-29 YR 1 TO 5	FEMALE 30-49 YR 1 TO 5	FEMALE 50-69 YR 1 TO 5	FEMALE 70+ YR 1 TO 5	MALE 16-29 YR 1 TO 5	MALE 30-49 YR 1 TO 5	MALE 50-69 YR 1 TO 5	MALE 70+ YR 1 TO 5
Improved 4+ Categories	0.0%	0.0%	0.4%	0.0%	0.8%	0.4%	0.4%	0.0%
Improved 2-3 Categories	3.9%	5.3%	3.7%	2.4%	5.2%	6.1%	2.2%	8.2%
Improved 1 Category	22.6%	19.8%	19.1%	18.3%	17.3%	21.0%	14.8%	19.0%
No Category Change	61.6%	57.6%	55.7%	37.1%	63.7%	54.7%	58.6%	45.1%
Declined 1 Category	10.8%	15.2%	18.4%	27.5%	11.4%	15.0%	15.9%	9.3%
Declined 2-3 Categories	0.8%	2.0%	1.6%	8.8%	1.4%	2.7%	7.4%	14.8%
Declined 4+ Categories	0.4%	0.0%	1.1%	6.0%	0.1%	0.0%	0.7%	3.5%

This chart depicts the proportion of the population (alive at 5 years post-injury) that improved or declined in cognitive function from Year 1 to 5, divided into sex and age subgroups. Females age 70 and over experienced the greatest decline in cognitive function, with 27.5% declining 1 category and 14.8% declining 2 or more categories. By contrast, 9.3% of males age 70 and over saw a 1 category decline, with 18.3% declining 2 or more categories.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
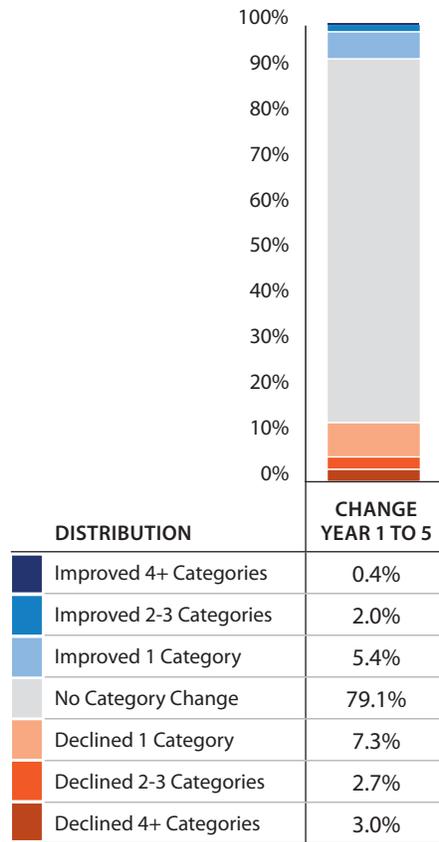
MOTOR
FUNCTION

DISTRIBUTION OF MOTOR FUNCTION AT 1 AND 5 YEARS POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	YEAR 1	YEAR 5
Independence	83.2%	76.6%
Modified Independence	8.3%	9.2%
Supervision	4.1%	4.9%
Minimal Assistance	1.2%	2.6%
Moderate Assistance	1.1%	2.1%
Maximal Assistance	1.4%	3.5%
Total Assistance	0.7%	1.1%

This chart depicts the comparison of Year 1 and Year 5 motor function in the population (alive at 5 years post-injury). The bar on the left indicates that 83.2% of individuals were independent at 1 year post-injury, with 4.4% needing assistance beyond supervision. As shown in the bar on the right, at Year 5 the independent group had dropped to 76.6%, with people requiring assistance beyond supervision increasing to 9.3%.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
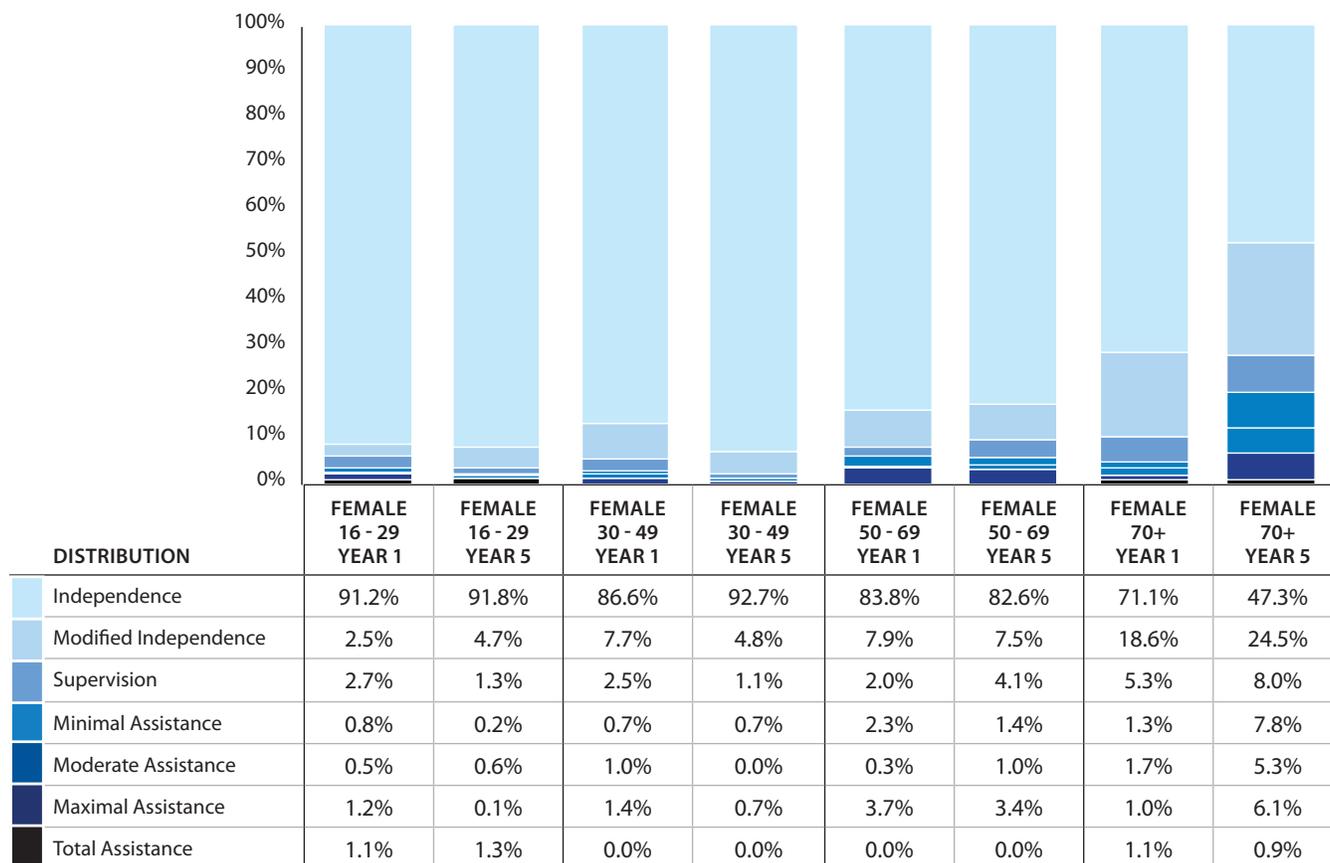
CHANGE IN MOTOR FUNCTION FROM YEAR 1 TO YEAR 5 POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	CHANGE YEAR 1 TO 5
Improved 4+ Categories	0.4%
Improved 2-3 Categories	2.0%
Improved 1 Category	5.4%
No Category Change	79.1%
Declined 1 Category	7.3%
Declined 2-3 Categories	2.7%
Declined 4+ Categories	3.0%

This chart depicts the proportion of the population (alive at 5 years post-injury) that improved or declined in motor function from Year 1 to Year 5. Between years 1 and 5, the majority of individuals (79.1%) experienced no change in motor function. Slightly more individuals declined 1 category (7.3%) than improved 1 category (5.4%), with 5.7% of individuals declining 2 or more categories and 2.4% improving 2 or more categories. Overall, 13.0% declined and 7.8% improved.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
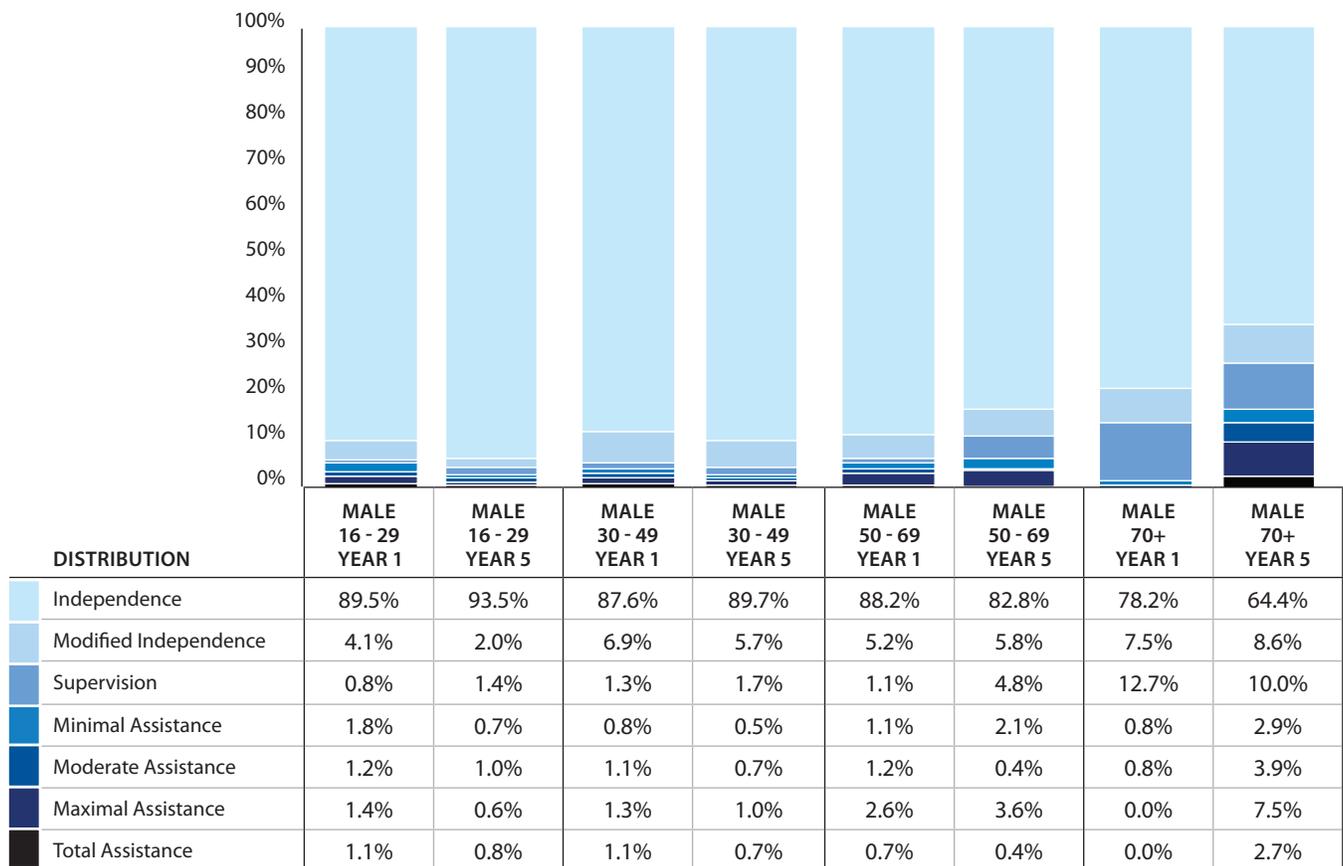
DISTRIBUTION OF MOTOR FUNCTION FOR FEMALES BY AGE AT 1 AND 5 YEARS POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	FEMALE 16 - 29 YEAR 1	FEMALE 16 - 29 YEAR 5	FEMALE 30 - 49 YEAR 1	FEMALE 30 - 49 YEAR 5	FEMALE 50 - 69 YEAR 1	FEMALE 50 - 69 YEAR 5	FEMALE 70+ YEAR 1	FEMALE 70+ YEAR 5
Independence	91.2%	91.8%	86.6%	92.7%	83.8%	82.6%	71.1%	47.3%
Modified Independence	2.5%	4.7%	7.7%	4.8%	7.9%	7.5%	18.6%	24.5%
Supervision	2.7%	1.3%	2.5%	1.1%	2.0%	4.1%	5.3%	8.0%
Minimal Assistance	0.8%	0.2%	0.7%	0.7%	2.3%	1.4%	1.3%	7.8%
Moderate Assistance	0.5%	0.6%	1.0%	0.0%	0.3%	1.0%	1.7%	5.3%
Maximal Assistance	1.2%	0.1%	1.4%	0.7%	3.7%	3.4%	1.0%	6.1%
Total Assistance	1.1%	1.3%	0.0%	0.0%	0.0%	0.0%	1.1%	0.9%

This chart depicts the comparison of Year 1 and Year 5 motor function in the female population (alive at 5 years post-injury), divided into age subgroups. Lighter colors indicate better outcomes than darker ones. As illustrated by the color patterns, most females were independent or had modified independence regardless of age or years post-injury. Less than 10% of females under age 70 needed supervision or assistance due to decreased motor function either at 1 or 5 years post-injury. Among females age 70 and over, the proportion needing supervision or assistance due to motor function was 10.4% at Year 1 and 28.1% at Year 5.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.
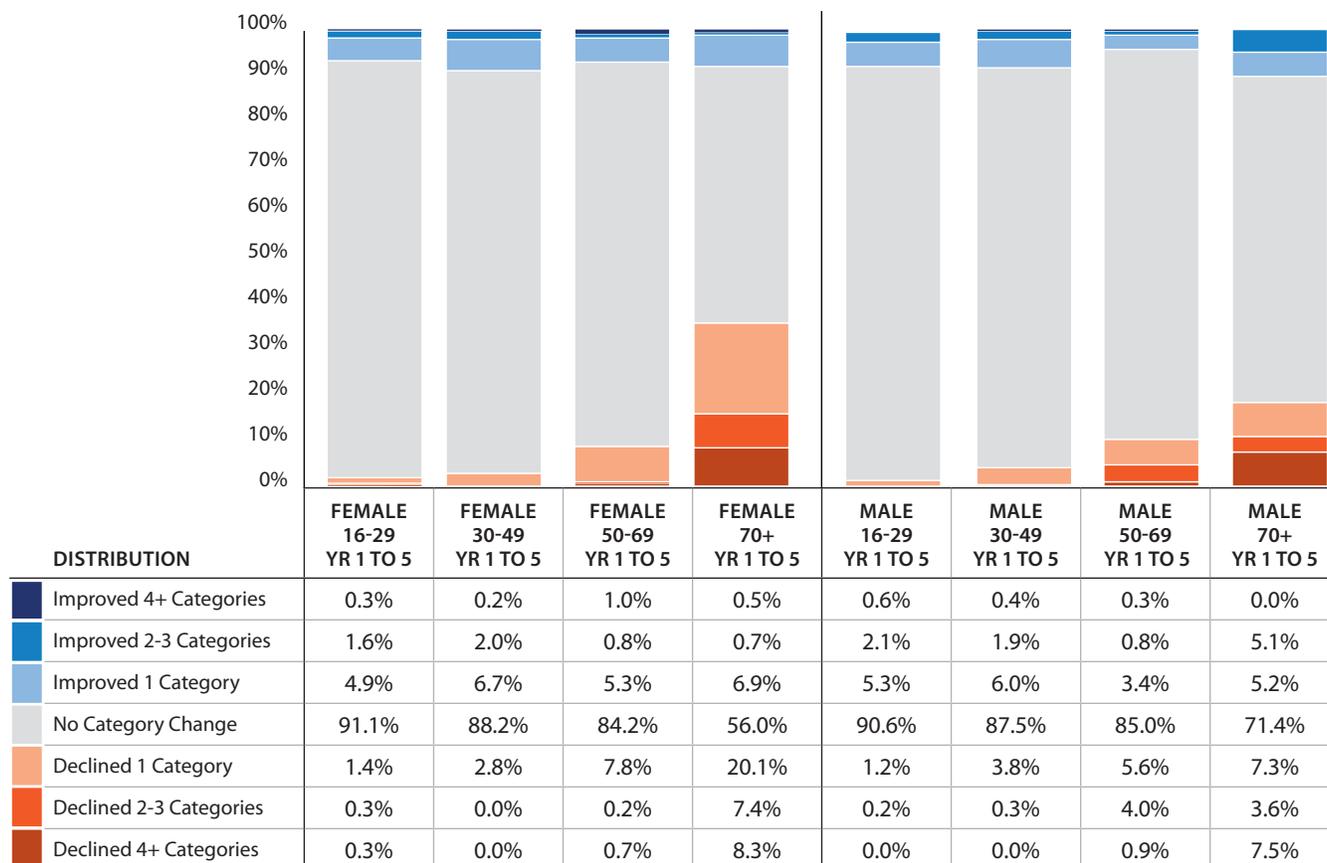
DISTRIBUTION OF MOTOR FUNCTION FOR MALES BY AGE AT 1 AND 5 YEARS POST-INJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	MALE 16 - 29 YEAR 1	MALE 16 - 29 YEAR 5	MALE 30 - 49 YEAR 1	MALE 30 - 49 YEAR 5	MALE 50 - 69 YEAR 1	MALE 50 - 69 YEAR 5	MALE 70+ YEAR 1	MALE 70+ YEAR 5
Independence	89.5%	93.5%	87.6%	89.7%	88.2%	82.8%	78.2%	64.4%
Modified Independence	4.1%	2.0%	6.9%	5.7%	5.2%	5.8%	7.5%	8.6%
Supervision	0.8%	1.4%	1.3%	1.7%	1.1%	4.8%	12.7%	10.0%
Minimal Assistance	1.8%	0.7%	0.8%	0.5%	1.1%	2.1%	0.8%	2.9%
Moderate Assistance	1.2%	1.0%	1.1%	0.7%	1.2%	0.4%	0.8%	3.9%
Maximal Assistance	1.4%	0.6%	1.3%	1.0%	2.6%	3.6%	0.0%	7.5%
Total Assistance	1.1%	0.8%	1.1%	0.7%	0.7%	0.4%	0.0%	2.7%

This chart depicts the comparison of Year 1 and Year 5 motor function in the male population (alive at 5 years post-injury), divided into age subgroups. Lighter colors indicate better outcomes than darker ones. As illustrated by the color patterns, most males were independent or had modified independence regardless of age or year post-injury. Less than 10% of males under age 50 needed supervision or assistance due to decreased motor function either at 1 or 5 years post-injury. Among males age 50-69, the proportion needing supervision or assistance due to motor function was also under 10% at Year 1, but 11.3% at Year 5. Among males age 70 and over, that proportion was 14.3% at Year 1 and 27.0% at Year 5.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.

CHANGE IN MOTOR FUNCTION BY SEX AND AGE FROM 1 TO 5 YEARS POSTINJURY AMONG 5-YEAR SURVIVORS OF MODERATE-TO-SEVERE TBI*

DISTRIBUTION	FEMALE 16-29 YR 1 TO 5	FEMALE 30-49 YR 1 TO 5	FEMALE 50-69 YR 1 TO 5	FEMALE 70+ YR 1 TO 5	MALE 16-29 YR 1 TO 5	MALE 30-49 YR 1 TO 5	MALE 50-69 YR 1 TO 5	MALE 70+ YR 1 TO 5
Improved 4+ Categories	0.3%	0.2%	1.0%	0.5%	0.6%	0.4%	0.3%	0.0%
Improved 2-3 Categories	1.6%	2.0%	0.8%	0.7%	2.1%	1.9%	0.8%	5.1%
Improved 1 Category	4.9%	6.7%	5.3%	6.9%	5.3%	6.0%	3.4%	5.2%
No Category Change	91.1%	88.2%	84.2%	56.0%	90.6%	87.5%	85.0%	71.4%
Declined 1 Category	1.4%	2.8%	7.8%	20.1%	1.2%	3.8%	5.6%	7.3%
Declined 2-3 Categories	0.3%	0.0%	0.2%	7.4%	0.2%	0.3%	4.0%	3.6%
Declined 4+ Categories	0.3%	0.0%	0.7%	8.3%	0.0%	0.0%	0.9%	7.5%

This chart depicts the proportion of the population (alive at 5 years post-injury) that improved or declined in motor function from Year 1 to Year 5, divided into sex and age subgroups. Females age 70 and over experienced the greatest decline in motor function, with 20.1% declining 1 category and 15.7% declining 2 or more. By contrast, 7.3% of males age 70 and over declined 1 category decline, with 11.1% declining 2 or more categories. The proportion of both females and males under age 50 improving in motor function was greater than those declining, but for both females and males age 50 and over the proportion declining was greater than those improving.

*Note: Includes cases with moderate-to-severe TBI receiving inpatient rehabilitation between 2001-2007 and followed for five years through 2012.

METHODOLOGICAL APPENDIX

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Recent publications by Corrigan and colleagues[3] and Cuthbert and colleagues[4] have provided a basis for deriving population estimates of persons 16 years and older in the United States who receive inpatient rehabilitation for a primary diagnosis of TBI. The Uniform Data System for Medical Rehabilitation[8] and the American Medical Rehabilitation Providers Association's eRehabData[9] serve as intermediaries between inpatient rehabilitation facilities and the Centers for Medicare & Medicaid Services. These organizations receive information on all patients treated in a rehabilitation facility (whether or not the patient has Medicare funding) and forward these data to the Centers for Medicare & Medicaid Services. Data from as much as 92% of all inpatient rehabilitation facilities, and a still higher percentage of all patients, are collected and reported by these 2 programs.[3] Corrigan and colleagues[3] (for the years 2001-2007) and Cuthbert and colleagues[4] (for the years 2001-2010) combined core data sets from the 2 intermediaries and compared the resulting U.S. population characteristics to the cohort enrolled in the TBI Model Systems National Database (TBIMS-NDB) for the same time periods. Both sets of analyses found overwhelming similarity between the U.S. population and the TBIMS cohorts after accounting for differences in the proportion of older adults. Among multiple individual differences and injury characteristics compared, important discrepancies were noted only for 1- to 9-day rehabilitation lengths of stay for both younger and older patients, and primary insurance and the proportion in the oldest age categories for the 65 years and older group. The minimal number of differences led to a common conclusion in both studies: with weighting, the TBIMS-NDB can be used to calculate population-level estimates for persons older than 15 years who received acute inpatient rehabilitation for a primary diagnosis of TBI in the United States.[3,4] While population characteristics can be directly extracted from the combination of the Uniform Data System for Medical Rehabilitation and eRehabData data sets, only a limited number of variables are available, and no information is collected beyond rehabilitation discharge. The ability to extrapolate population estimates from the TBIMS-NDB allows a richer array of characteristics to be estimated, including outcomes post-injury, at 1, 2, 5, and every 5 years thereafter. The TBIMS-NDB includes medical record–verified cases of moderate and severe TBIs admitted for inpatient rehabilitation at a TBIMS center.[10]

The National Institute on Disability, Independent Living and Rehabilitation Research has funded the TBIMS program since 1987. Central to this program is a standardized, longitudinal database for studies of TBI treatment and outcomes started in 1987.[11] In the TBIMS-NDB, TBI is defined as damage to brain tissue caused by an external mechanical force as evidenced either by medically documented loss of consciousness or posttraumatic amnesia due to brain trauma or by objective neurological findings that can be reasonably attributed to TBI on physical examination or mental status examination. In addition to having incurred a TBI meeting the aforementioned definition, additional inclusion criteria are as follows: (1) meet at least 1 of the following criteria for moderate-to-severe TBI: posttraumatic amnesia greater than 24 hours, trauma-related intracranial neuroimaging abnormalities, loss of consciousness exceeding 30 minutes, or a Glasgow Coma Scale score in the emergency department of less than 13 (unless due to intubation, sedation, or intoxication); (2) be at least 16 years of age at the time of injury; (3) present to an acute care hospital within 72 hours of injury; (4) receive both acute hospital care and comprehensive rehabilitation in a designated brain injury inpatient unit within the TBIMS; and (5) provide informed consent to participate or have a proxy provide consent.[10] Data are recorded during inpatient rehabilitation and subsequently during follow-up interviews at 1, 2, and 5 years post-injury and every 5 years thereafter. The TBIMS data collection protocol uses a "best source" policy for interviewing a proxy when the individual is not able to provide valid information.[10]

Measures that require reporting of a subjective state (e.g., life satisfaction, emotional state) are collected only from the individual with a TBI. As of March 31, 2016, the TBIMS-NDB contained 14,633 cases and had a follow-up rate of 82% for follow-up interviews conducted up to 25 years post-injury; 83% for just those at 5 years.

The current report used the Corrigan and colleagues 2001-2007 compilation of the U.S. population receiving rehabilitation for TBI to weight the 4,838 TBIMS-NDB cases admitted and discharged between October 1, 2001, and December 31, 2007 (with 1 and 5 year post-injury follow-up data collected between 2002 and 2013).[12] In the first step, the TBIMS-NDB cases were weighted using raking, an iterative proportional weighting procedure that repeats until a sample distribution closely matches that of a larger population across numerous population characteristics simultaneously.[13] In this first raking and weighting procedure, sample distributions were the characteristics of the TBIMS-NDB, and the population values were the categorical characteristics of the U.S. TBI Rehabilitation population included in the article by Corrigan and colleagues.[12] Variables included as part of this raking and weighting procedure were age, sex, race/ethnicity, marital status, primary payment source, rehabilitation length of stay, and FIM motor and cognitive scores. Within the TBIMS-NDB, missing values for variables were rare (<10%); however, those individuals with missing data across any of these variables had the missing value imputed using expectation maximization[14] prior to the implementation of the raking procedure. At the completion of raking, all case weights were evaluated using weight trimming, a process in which weights of extreme values are truncated to less extreme values (e.g., 1%-5%), with the intent of reducing the mean squared error for outcomes of interest. For these analyses, weight trimming was not found to reduce the mean squared error for any of the outcomes; thus, the weights were applied in their original configuration. In the TBIMS-NDB weighted sample, 20% expired by their 5th anniversary of injury. For the supervision, cognitive function, and motor function charts in this report, surviving cases were further limited to individuals with complete follow-up data at all time points and a second round of raking and weighting was used to adjust the remaining cases with complete follow-up data to the characteristics of all surviving cases. All raking and weight trimming analyses were completed with SAS (version 9.3), using the IHB raking macro.[15]

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