

2. Epidemiology and Long-term Outcomes Following Acquired Brain Injury

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Abbreviations

ABI	Acquired Brain injury
ALC	Alternative level of care
GCS	Glasgow Coma Scale
MVA	Motor Vehicle Accidents
nTBI	Non-Traumatic Brain Injuries
TBI	Traumatic Brain Injury

2.1 Epidemiology of Acquired Brain Injury

2.1.1 Incidence and Prevalence

Acquired brain injury (ABI), particularly traumatic brain injury (TBI), is one of the leading causes of death and lifelong disability in North America (Greenwald et al. 2003; Pickett et al. 2001; Thurman & Guerrero 1999). In the United States between 1.4 and 1.7 million people sustain a TBI every year (Faul et al. 2010; Zaloshnja et al. 2008), with more than 120,000 people expected to develop long-term disabilities (Zaloshnja et al. 2008). In the province of Ontario, more than 80,000 individuals sustained a TBI between 2002 and 2006 (Colantonio et al. 2010). Among low and middle income countries, the lifetime prevalence of TBI ranged from 0.3% in China to 14.6% in rural Mexico (Khan et al. 2015).

Most individuals with TBI have milder injuries, but residual deficits in these patients are not uncommon (Thornhill et al. 2000). Moreover, 10-15% of patients with TBI have more serious injuries requiring specialist care (Maas et al. 2008). The frequency of injuries of moderate severity are increasing, with the proportion of moderate TBIs being 19% in 1992 and increasing to 37% in 2002 (Colantonio et al. 2009). Unfortunately, the incidence of TBI is expected to increase due to the ongoing demographic shift of an aging population (Colantonio et al. 2009).

Much of the data pertaining to ABI is collected from a specific point of care (i.e., emergency departments, inpatient rehabilitation, and outpatient services). It should be noted that because these studies do not explore the number of patients treated in other healthcare settings, and the number of individuals who go untreated are not accounted for, the number of individuals with a brain injury is likely to be higher than these figures suggest (Langlois et al. 2006).

2.1.2 Gender Differences

The rate and etiology of injury seem to differ between genders, with TBI being more common in men (Canadian Institute for Health Information 2007; Colantonio et al. 2009; Colantonio et al. 2010; Greenwald et al. 2003). A study found that in the United States, TBI was nearly 1.4 times more common among males than females (Faul et al. 2010). Data from Ontario, Canada also shows greater rates of TBI among males (Chan et al. 2013a). The increased incidence in men may be due to greater participation in risk-taking activities, exposure to occupational hazards, and more engagement in violent behaviours than women. A cohort study found that fall-related TBIs were more common among females than males (51.7% versus 36.2%, respectively); conversely, being struck by or against an object was more common among males than females (Colantonio et al. 2010). Females have also been shown to have 33.1% lower odds of mortality after adjusting for covariates than males post brain injury (Haring et al. 2015). While another study in Spain found no gender effects for poorer outcome after severe TBI (Herrera-Melero et al. 2015).

2.1.3 Age and TBI

Overall, motor vehicle or related transportation accidents (MVAs) and falls are the most common causes of TBI among all age groups (Faul et al. 2010). Falls and MVAs, together, were shown to account for approximately 75% of TBIs requiring hospitalization in Ontario from 1992 to 2002 (Colantonio et al. 2009). Based on literature, falls account for approximately 35% to 42% of TBIs whereas MVAs are responsible for 12% to 17% (Colantonio et al. 2010; Faul et al. 2010).

Evidence suggests that the etiology of TBI varies with age. At one end of the spectrum are children, with a common cause of injury being non-accidental head trauma (Greenwald et al. 2003); up to two thirds of severe brain injury cases in the 0-4 year old age group were attributable to non-accidental trauma (Greenwald et al. 2003). Among low and middle income countries, younger age has been associated with a higher prevalence rate of TBI (Khan et al. 2015). Among adults, MVAs account for more than 60% of TBIs in those aged 16-25 years and 47% of TBIs in those aged 26-35 years (Colantonio et al. 2009). Children and older adults are more susceptible to injury due to falls (Colantonio et al. 2009; Faul et al. 2010). An epidemiological study conducted in the United States showed that falls accounted for 50.2% of TBIs in children (aged 0-14 years) and 60.7% of TBIs in adults aged 65 years or older (Faul et al. 2010). For those 85 years of age or older, the rate of hospitalizations in Ontario for TBIs due to falls was as high as 90% (Chan et al. 2013b). The increased risk of falls in the elderly may be linked to factors such as substance use, decreased balance and/or age-related neurological conditions such as dementia (Wagner 2001).

With increasing age, the prevalence of non-traumatic brain injuries (nTBIs) also increases; nTBIs, which exclude a primary stroke diagnosis, are more prevalent in those over the age of 40 years. In Ontario, the rate of hospitalized nTBI episodes increased with age, whereby the rates were 365 persons per 100,000 for those 65-74 years old compared to 561 persons per 100,000 for those above 85 years old (Chan et al. 2013b). Vascular insults (not captured in other national studies on stroke), brain tumours, meningitis, encephalitis, and anoxia have been found to be the most frequent causes of nTBI (Chan et al. 2013b).

There is an emerging trend of increased rates of TBI among elderly individuals which is heavily influenced by the fact that they are the fastest growing sector of the population (Chan et al. 2013a). A recent examination of the Ontario ABI Dataset found that between 2003 and 2010, there was a significant increase in TBI episodes among patients 65 to 74 years (11%), 75 to 84 years (50%) and those aged 85 years and older (63%; Chan et al. 2013a). Recent studies examining data from the United States also suggest that the highest rates of TBI were among those aged 75 years or older (Cuthbert et al. 2015; Faul et al. 2010).

2.1.3.1 Impact of Older Age on TBI and Subsequent Recovery

Those who sustain a TBI, regardless of age, may develop circulatory, digestive, or respiratory problems; have an increased risk of infection; and experience neurological complications, ranging from endocrine problems to seizures, and swallowing difficulties (Flanagan 2008). Individuals with TBI may also develop mental health concerns such as depression (Colantonio et al. 2011).

Evidence suggests that age influences the trajectory of one's recovery following injury. Individuals in the older age bracket generally had poorer outcomes when compared to younger individuals (Marquez de la Plata et al. 2008). Pennings et al. (1993) found individuals over the age of 60 required a greater number of resources to obtain favourable outcomes compared to younger patients (≤ 40 years old) with a similar severity of injury. For those in the older age group, a longer length of stay in hospital was often necessary to address their slower rate of functional recovery (Chan et al. 2013a; Cifu et al. 1996). Both admission and discharge Functional Independence Measure scores from inpatient rehabilitation were lower among older adults (Chan et al. 2013b). Consequently, older adults also had a lower rate of discharge to the community (Colantonio et al. 2009).

Older age at the time of injury has also been associated with poorer performance on various cognitive domains (Senathi-Raja et al. 2010). A study by Ashman and Mascialino (2008) specifically noted that deficits in encoding and retention of verbal information, as well as inattention, were more common and more serious post TBI in those over the age of 65. It has been postulated, for those who are older at time of injury, less neuronal plasticity may negatively affect the brain's ability to compensate or adapt in the same way a younger brain does post injury (Senathi-Raja et al. 2010).

Mosenthal et al. (2002) found older subjects (>64 years of age) had a significantly higher mortality rate than their younger peers regardless of the severity of TBI sustained ($p < 0.001$). Study authors suggested this increase in mortality may be attributable to multiple factors including pre-existing comorbidities, post-injury complications, and the intrinsic properties of aging itself (Mosenthal et al. 2002). Evidently, for older patients with TBI, their recovery may be challenging. This is largely because aging is often accompanied by a number of chronic comorbidities (e.g., diabetes, arthritis, cardiovascular disease and/or cerebrovascular disease; Colantonio et al. 2011). Such factors are rarely taken into account when assessing the impact an ABI has on an older person (Colantonio et al. 2004; Rapoport & Feinstein 2000); however, these pre-existing health issues may impede the recovery of patients living with an ABI if left unresolved.

A recent study examined the recovery of patients with TBI in inpatient rehabilitation facilities (Dijkers et al. 2013). The study found that adults aged 65 years or older who had less severe injuries received fewer hours of therapy and had shorter lengths of stay compared to other patients with TBI. These patients gained less functional ability during their stay and were likely to have a higher mortality rate (Dijkers et al. 2013). Hence, issues regarding therapy intensity and care may be important when examining successful recovery potential among older adults.

2.1.3.2 Impact of Aging with an Established ABI

Few studies have examined the effects of ABI on life expectancy; however, it has been suggested that a person with TBI who recovers during the acute period may still have a substantially reduced life expectancy and a poorer outcome (Colantonio et al. 2009; Ratcliff et al. 2005). One of the strongest predictors of post-acute mortality is the patient's age at the time of injury (Colantonio et al. 2009). Sustaining an ABI in the younger years may shorten one's life by 10 years (Corrigan et al. 2007). Further, Ratcliff et al. (2005) found an ABI doubled long-term mortality risk for all age groups, even though many survived 20 or more years post injury. It is also important to consider that persons with TBI may be at risk for subsequent falls due to balance, mobility, and cognitive impairments, as well as environmental challenges. Coupled with the effects of aging, these risk factors together may result in a patient sustaining yet another injury (Chan et al. 2013c).

2.1.4 The Impact of ABI on Survivors and the Healthcare System

Assessing the impact that an ABI may have on individuals as they age is difficult as survivors can live for several decades post injury. This is particularly true for children and adolescents who sustain an injury. Unfortunately, longitudinal studies assessing the impact of the injury on the individual and their families is challenging due to the cost, and the number of participants lost to follow-up.

To provide some perspective on the financial burden associated with injury, the annual medical costs of patients hospitalized with a TBI in Ontario, in the first year of follow up, was approximately \$120.7 million, which translates into a mean cost of \$32,132 per patient (Chen et al. 2012). The cost, including

follow-up services (e.g. inpatient rehabilitation), exceeded \$150,000 per patient. These injuries are costly to the system, and unfortunately some costs are a result of alternative level of care (ALC) days. ALC is when patients occupy hospital beds even when they do not require the level of intensity of resources/services being provided in that particular care setting (Chen et al. 2012); for example, this commonly occurs while patients are awaiting a placement in a long-term care facility. In Ontario, from 2007 to 2009, the total number of days spent as ALC among patients with TBI increased from 15,606 to 22,637 days (Chen et al. 2012). Furthermore, the use of health care resources may also depend on multiple factors. Fu et al. (2015) found, in Canada, there was a 29% increase in hospitalization among those aged 65 years or older with TBI between the years 2006 and 2011. Hammond et al. (2015) found that this increased risk of rehospitalization was related to older age, history of seizures, history of brain injuries, and other comorbid medical conditions. Rural residence and psychiatric comorbidity have also been shown to be predictors of rehospitalization (Saverino et al. 2016).

Unfortunately, data indicates that a large proportion of individuals with a brain injury do not appear to be accessing all the rehabilitation services that they need. The Ontario Brain Injury Association survey conducted in 2005 examined the number of individuals using services compared to those who aren't (OBIA 2007). The main reasons given for the gaps between service need and use were long waiting lists, lack of available and appropriate services, lack of training about the cognitive and behavioural needs of patients, and poor coordination of services (Chen et al. 2012; Minnes et al. 2010). Particularly noteworthy is the apparent lack of access to services for psychological issues; those with pre-existing comorbid conditions, such as psychosocial and psychiatric problems, are at an increased risk of mortality following injury (Colantonio et al. 2009), and thus should have access to care in a timely manner.

2.1.5 Mortality and ABI

Individuals with ABI have lower life expectancies than matched individuals. Harrison-Felix et al. (2015) found that between 2001 and 2010, individuals with TBI were 2.23 times more likely to die compared to individuals with similar age, sex, and race and those with TBI had an average reduced life expectancy of 9 years. Older age, male, unemployed at injury, married at injury, and less than high school education have been shown to be risk factors for earlier death among those with ABI (Cuthbert et al. 2015; Harrison-Felix et al. 2015). Mortality rates range from 24.5% among younger individuals and 40.9% among older persons (Walder et al. 2013). Fifty-four percent of adults over 55 years die within 6 months of discharge and 68% within 1 year (Peck et al. 2014).

2.2 Prognostic Indicators

For ABI rehabilitation, it is important to know which prognostic indicators are significantly related to outcomes. Prognostic indicators can include such variables as injury severity, etiology of injury, age, rehabilitation length of stay, duration of post-traumatic amnesia, etc. Table 2.1 summarizes the most common TBI prognostic indicators identified in the literature.

Table 2.1 Common Prognostic Indicators for ABI

<ul style="list-style-type: none"> • Age • Gender • Presence of prior brain injury • Injury severity • Length of coma • Initial Glasgow Coma Scale (GCS) score • Injury etiology 	<ul style="list-style-type: none"> • Rehabilitation length of stay • Duration of post-traumatic amnesia • Timing of rehabilitation • Intensity of rehabilitation • Nature of injury (TBI versus nTBI) • Presence of comorbidities
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Bushnik et al. (2003) focused on a variety of etiologies, such as MVAs, assaults, and falls. They demonstrated that individuals involved in MVAs initially incurred more severe injuries than individuals injured by assaults, falls, or other causes. However, at one year post-injury individuals with TBI related to MVAs reported the best functional and psychosocial outcomes, while individuals with violence-related TBI reported the highest unemployment rates and lowest Community Integration Questionnaire scores (Bushnik et al. 2003). Individuals with TBI related to falls or ‘other’ etiologies had outcomes that fell somewhere between those injured by MVAs and assaults. This occurred despite the fact there were no functional differences between the groups at discharge from rehabilitation.

Asikainen et al. (1998) focused on the effects of hospital admission Glasgow coma scale (GCS) score, length of coma, and duration of post-traumatic amnesia on outcomes. While hospital admission GCS score positively correlated with functional outcome, as measured by Glasgow Outcome Scale scores, length of coma and duration of post-traumatic amnesia correlated with both functional and occupational outcomes. Poor scores on functional measures (e.g., mobility, eating, or grooming) have also been found to be significant predictors of premature death (Colantonio et al. 2008). Notably, limitation in eating was one of the most important predictors of mortality (Ratcliff et al. 2005).

The nature of the injury seems to play a predictive role in patient outcomes as well. For instance, Colantonio et al. (2011) reported that the diagnosis of nTBI was associated with a lower Functional Independence Measure rating at admission and at discharge, more comorbidity diagnoses, and longer lengths of stay in inpatient rehabilitation. Significantly more nTBI patients died in acute care, whereas more patients with TBI were discharged home, to inpatient rehabilitation care, or to a long term care facility (Chan et al. 2013c).

The presence of comorbidities may affect patient outcome as well. Having a psychiatric comorbidity increased the odds of having an ALC day among patients with TBI by 73% (Chen et al. 2012). Similarly, increasing Charlson Comorbidity Index category increased the odds of having an ALC day by 9% in the TBI population. A study by Rapoport et al. (2000) demonstrated that major depression in older adults in the first months after TBI had persisting adverse effects on outcome. This finding is particularly problematic since studies have demonstrated that major depression is quite common in the TBI population, and associated with negative prognosis (Rogers & Read 2007).

2.3 Long-Term Outcomes

There is increasing concern of the development of neurodegenerative diseases many years after sustaining a TBI due to the physiological changes that occur following injury. The Institute of Medicine (2009) has concluded that there is an association between moderate and severe TBIs with Alzheimer’s and Parkinson’s disease. Veterans that sustained a TBI were at an increased risk for Alzheimer’s disease and dementia (Plassman et al. 2000). In individuals over the age of 55 years, this pattern was present for

even a single presentation of a moderate to severe TBI (Gardner et al. 2014). Furthermore, individuals that sustained a TBI were also at an increased risk for Parkinson’s disease, particularly with multiple TBIs (Goldman et al. 2006). Additional research is needed.

In an attempt to examine the long-term impact of ABI, some of the most salient studies related to long-term outcomes were identified and reviewed. Participants’ follow-up periods ranged from three months to more than ten years. The studies included in the review were separated into two groups according to participants’ injury severity: 1) moderate to severe ABI (when both moderately and severely injured participants were included in the study) and 2) severe ABI (when only severely injured participants were included in the study). Studies were also separated according to three follow-up periods: 1) three months to two years, 2) three to five years, and 3) greater than five years. Results are summarized in Tables 2.2 to 2.4 below.

Individual Studies

Table 2.2 Long-Term Outcomes Up to Two Years Post Injury

Moderate to Severe ABI	
Author/Year/ Country/N	Study Summary
Novack et al. (2000) USA N=72	Population: 72 individuals with TBI; >50% severe injury. Follow-up: 6 and 12mo post injury. Findings: For individuals with severe TBI, driving status improved only marginally from 6 mo (n=11) to 12 mo (n=16) (p=0.05); the total number of individuals with >20 hr/wk employment increased from 1 (2.0%) at 6 mo to 5 (10.2%) at 12 mo; and a trend towards increased productive activities (8.2% at 6mo vs. 16.8% at 12mo, p=0.04).
Malec et al. (1993) USA N=29	Population: 29 individuals with ABI (TBI=20) participating in post-acute rehabilitation. Mean age at admission=33.1yr; mean time post-injury=1463.9d. Follow-up: 1yr (n=21). Findings: 86% of patients were living with no supervision compared to 48% on admission. 48% of patients were in an independent work placement and 29% were unemployed.
Cope et al. (1991) USA N=145	Population: 145 individuals with ABI (TBI=113) admitted to post-acute rehabilitation; mean age=35yr; mean time post-injury=448d; mean disability rating score=6.03). Follow-up: 6, 12, and 24 mo post discharge. Findings: From admission to follow-up there was an increase in residence at home (44.8% to 69.7%), an increase in competitive employment or academic involvement (5.6% to 34.5%), a decrease in ‘no productive activity’ (92.3% to 27.6%), and an increase in the percentage of patients independent throughout a 24h period (25% to 78.6%). All differences were significant (p<0.0001).
Severe ABI	
Author/Year/ Country/N	Study Summary
Harrick et al. (1994) Canada N=21	Population: 21 individuals with severe TBI. Follow-up: 1yr. Findings: 62% (vs. 34% at admission) were engaged in productive activity. Financially 10% (vs. 5% at admission) were self-supported, 24% (vs. 5% at admission) were both self-supported and aided, and 62% (vs. 81% at admission) were aided. Moreover, 81% (vs. 68% at admission) received informal support, 19% (vs. 10% at admission) received partial support, and no one (vs. 24% at admission) required institutional support.

<p>Mills et al. (1992) USA N=42</p>	<p>Population: 42 patients with TBI; GCS score <9. Follow-up: 6mo (n=32), 12mo (n=13), and 18mo (n=18) post-discharge from community cognitive rehabilitation program. Findings: At 6mo follow-up, 87.5% of patients maintained or improved their status in the home and community, and 90% maintained or improved their status in leisure and vocational function. These gains were maintained or improved at a follow-up of 12 and 18 mo.</p>
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Table 2.3 Long-Term Outcomes at Three to Five Years Post Injury

Severe ABI	
Author/Year/Country/N	Study Summary
<p>Katz et al. (2009) USA N=36</p>	<p>Population: 36 patients with ABI (TBI=22). Follow-up: 2 and 4yr. Findings: Of 16 patients who were assessed at 2yr follow-up, Disability Rating Scale (DRS) scores continued to improve compared to admission in 56% of patients. Between 2yr and 4yr, improvement was seen in 3 of 8 patients. Of 23 patients followed 1 to 4yr, 43% achieved household independence, and 22% returned to work or school.</p>
<p>Kaitaro et al. (1995) Finland N=19</p>	<p>Population: 19 patients with severe TBI. Follow-up: 5yr. Findings: None of the participants required institutional care. 68% were living with their families or spouses, and 89% were retired despite attempts to work.</p>
<p>Harrick et al. (1994) Canada N=21</p>	<p>Population: 21 individuals with severe TBI. Follow-up: 3yr. Findings: 67% (vs. 34% at admission) were engaged in productive activity. Financially, 15% (vs. 5% at admission) were self-supported, 15% (vs. 5% at admission) were both self-supported and aided, and 73% (vs. 81% at admission) were aided. Moreover, 77% (vs. 68% at admission) received informal support, 24% (vs. 10% at admission) received partial support, and no one (vs. 24% at admission) required institutional support.</p>

Table 2.4 Long-Term Outcomes at Greater than Five Years Post Injury

Moderate to Severe ABI	
Author/Year/Country/N	Study Summary
<p>Klonoff et al. (2001) USA N=164</p>	<p>Population: 164 patients with ABI (TBI=113). Follow-up: 11yr. Findings: 83.5% were productive in some capacity. Of these, 46.3% were gainfully employed full-time, 11.6% were in full-time school or school/work, and 9.2% were in part-time gainful work or school. Another 12.2% worked as volunteers and 16.5% were not productive in any capacity. Additionally, younger age (p=0.009), being male (p=0.025), and higher staff working alliance ratings of patients (p=0.024) and their families (p=0.017) were associated with better vocational/school outcomes.</p>
Severe ABI	
Author/Year/Country/N	Study Summary
<p>Possl et al. (2001) Germany N=43</p>	<p>Population: 43 participants with severe ABI. Follow-up: 7-8yr. Findings: 37% had achieved stable re-employment at pre-injury level, 16% had achieved stable re-employment after modifications of work, 19% continued to have persistent vocational adjustment problems, and 28% opted for retirement.</p>

Johnson (1998) UK N=64	Population: 64 patients with severe head injury. Follow-up: 10yr or more. Findings: 42% had re-established themselves in employment, 20% had an irregular pattern of work and the remainder were not in the workforce.
Wilson (1992) UK N=25	Population: 25 patients. Follow-up: 5-10yr. Findings: 81% were living in their own homes either alone, with relatives, or with friends. The remaining were in long-term residential care, residential college, or warden controlled accommodation. 42% were in paid employment; 1 of 11 were in paid employment that was comparable to their pre-injury status.

Table 2.5 summarizes whether each long-term outcome study reported a positive or negative outcome regarding participants' productivity, independence, and place of residence. Productivity outcomes were defined as positive if the majority ($\geq 50\%$) of participants were involved in any form of paid or unpaid labour, including volunteer work. If the majority of participants were not taking part in any of the aforementioned types of productive activity (e.g. they were retired) then it was considered a negative outcome. Independence was related to the level of supervision required. Positive outcome was noted as long as the majority of participants did not require institutional care or support. However, if the majority of participants did require this type of assistance it was deemed a negative outcome. Positive place of residence outcomes were defined as the majority of participants in the study not living in an institutional setting. Otherwise, it was considered a negative outcome. Positive trends and increases regarding productivity, independence, and place of residence were also viewed as positive outcomes.

Individual Studies

Table 2.5 Long-Term Outcomes for Productivity, Independence, and Place of Residence

Author/Year/ Country	Injury Severity	Follow-Up Period	Productivity	Independence	Place of Residence
Cope et al. (1991) USA	moderate to severe ABI	3mo-2yr	+	+	+
			(no deterioration in positive trends from 6-24mo)	(no deterioration in positive trends from 6-24mo)	(no deterioration in positive trends from 6-24mo)
Malec et al. (1993) USA	moderate to severe ABI	3mo-2yr	+	+	n/a
			(72%)	(96%)	
Klonoff et al. (2001) USA	moderate to severe ABI	>5yr	+	n/a	n/a
			(83.5%)		
Novack et al. (2000) USA	severe ABI	3mo-2yr	+	n/a	n/a
			(12.6% increase in those involved in productive activity from 6-12mo)		
Mills et al. (1992) USA	severe ABI	3mo-2yr	+	n/a	n/a
			(90%)		
Harrick et al. (1994) Canada	severe ABI	3mo-2yr	+	+	+
			(62%)	(100%)	(100%)

Author/Year/ Country	Injury Severity	Follow-Up Period	Productivity	Independence	Place of Residence
Harrick et al. (1994) Canada	severe ABI	3-5yr	+ (67%)	+ (100%)	+ (100%)
Kaitaro et al. (1995) Finland	severe ABI	3-5yr	- (89%)	n/a	+ (100%)
Wilson (1992) UK	severe ABI	>5yr	- (42%)	+ (81%)	+ (81%)
Johnson (1998) UK	severe ABI	>5yr	+ (62%)	n/a	n/a

Note: +=positive outcome; -=negative outcome; n/a=not applicable; (%)=Percentage of participants who experienced positive/negative outcome.

In summary, although methodological differences between the various studies do not permit direct comparison, it is generally true that those who have moderate to severe ABI appear to fare better than those with exclusively severe ABI on the dimension of productivity in particular. Moreover, even those who have severe ABI might expect to have generally favorable outcomes with respect to return to independent living.

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