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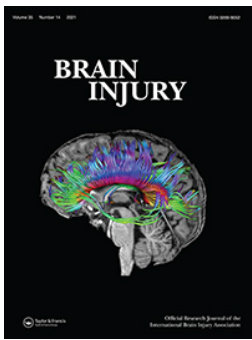
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Self-reported outcomes and patterns of service engagement after an acquired brain injury: a long-term follow-up study

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Self-reported outcomes and patterns of service engagement after an acquired brain injury: a long-term follow-up study

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ABSTRACT

Primary Objective: To describe the clinical characteristics, self-reported outcomes in domains relating to activities of daily living and patterns of service engagement in the survivors of a moderate-to-severe acquired brain injury over seven years.

Research Design: A longitudinal research design was used.

Methods and Procedures: Thirty-two individuals who sustained a moderate-to-severe acquired brain injury completed a Sociodemographic and Support Questionnaire at one (t1) and seven years (t2) after completing a publicly funded inpatient neurorehabilitation program.

Main Outcomes and Results: There were minimal changes in independent living, mobility, ability to maintain key relationships and in return to work in the interval between t1 and t2. Sixty-nine percent of participants engaged with two or more allied health professional services and 75% engaged with support services in the community over the seven years.

Conclusions: There were minimal additional gains in outcomes relating to activities of daily-living and there was a high level of service need in the first decade postinjury. Young and middle-aged individuals who sustain an ABI may continue to live in the community for decades with some level of disability and may require ongoing access to services.

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Introduction

While outcomes after acquired brain injury (ABI) are variable, illustrating the heterogeneity of the condition, there are well-documented long-term neurological, physical, cognitive, emotional, and behavioral sequelae from which some people never fully recover (1,2). Impairments related to ABI, depending on their severity, can limit an individual’s ability to live independently, to return to work or education, to participate in leisure or social activities, to fulfil family roles and to maintain key relationships (3).

In the ABI literature, some studies describe individual’s abilities to live independently while others describe their level of independence in terms of self-care and in carrying out activities of daily living such as domestic tasks, using public transport and driving. Short- (4,5) and more long-term follow-up studies (1,6,7) describe increasing levels of independence in carrying out these activities over time in the years after injury. As much of the neurological recovery after brain injury tends to happen in the first two years after injury; it follows there are large increases in the proportion of individuals who achieve independence in this interval (4) with fewer additional gains potentially to be made over the longer-term (1,6,7). Many individuals who survive an ABI also make a good physical recovery, with between 75% and 85% of individuals reporting high levels of mobility in the first six- to ten-years postinjury

(1,5,7). Together, these studies suggest that in the days, weeks, months and early years that follow ABI, most people require some level of practical support to manage daily living.

With respect to marital status, Norup, Kruse (8) found that individuals who had experienced TBI were at an increased risk of divorce in the first three years postinjury. More long-term studies suggest that there are minimal changes in marital status in the years after injury (1,5). However, marital status as a measure of “relationship” does not adequately capture their inherent complexity (9,10). Several studies suggest that while marital status might be stable in the years after ABI, that individuals may experience poorer quality of interpersonal and couple relationships, greater interpersonal difficulties, and social isolation (1,5).

The rates of return to work after an ABI are also poor, with less than half of survivors of ABI returning to work within two years of injury (1,4,11). Rates of return to work do not improve with time, with poor rates also observed over the longer-term (1,6,7,12). This is concerning given that some 75% of survivors of ABI are thought to be of working age (13). Pre-injury employment status and return to work after ABI may play an important role in mediating the level of disability, global functional outcomes and mental health outcomes over the longer-term after ABI (2,14–16). For example, in the first five years after moderate-to-severe TBI, Forslund, Roe (14) demonstrated that those who had been employed pre-injury showed a decrease in disability over time and those

who had been unemployed pre-injury showed an increase in disability over time. Furthermore, in the first decade post-injury, Forslund, Perrin (2) demonstrated that among other demographic and injury characteristics such as younger age and shorter duration of post-traumatic amnesia, that pre-injury employment status, was associated with better global functional outcome after a moderate-to-severe TBI. Two systematic reviews also concluded that there may be some association between demographic and injury characteristics such as return to work and age, level of education, employment history, gender, race, the severity of the injury and the presence of mood difficulties (15,16). In turn, demographic and injury characteristics such as gender, relationship status at the time of injury, professional occupation and the severity of the brain injury may be predictive of an individual's employment status in the first ten years after a moderate-to-severe ABI (12).

It has long been acknowledged in the literature that access to specialized, intensive neurorehabilitation services offered by multi-disciplinary teams is critical to minimizing ABI impairments and to optimizing outcomes (17–19). Yet despite the existence of published national strategies such as “The National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011–2015” (20) and “The National Strategy and Policy for the Provision of Neuro-Rehabilitation Services in Ireland, Implementation Framework 2019–2021” (21), ABI services in Ireland continue to face several serious challenges. These challenges include but are not limited to: long waiting lists, limited access to specialist rehabilitation, a lack of community-based specialist rehabilitation, inappropriate use of acute hospital beds and the inappropriate placement of young people into nursing homes due to a shortage of services in the community (18,21). With this in mind, it is unsurprising that the family members of survivors of ABI, services providers, and expert stakeholders describe the ABI care pathway in Ireland as a “fragmented,” “geographic lottery” of a system that is lacking in coordination and communication (5,22,23). Burke, McGettrick (18) highlighted that the lack of basic data available on the ABI population is an important barrier to policy development, service planning and delivery both in Ireland and abroad. These challenges to ABI service delivery are not unique to Ireland. Johnstone, Nossaman (24) concluded that geographical location also has a significant bearing on individual's ability to access support services after ABI in the American healthcare system and that the services available over the long-term often do not meet the clinical need. Echoing this, Andelic, Forslund (25) concluded that over a ten-year period service use was lower than would be expected given the sequelae associated with moderate-to-severe TBI; suggesting that the traditional model of rehabilitation service delivery was not meeting the known long-term needs of service users in Norway. Together these data suggest that the ability to access ABI services may be contingent on the healthcare system accessed such that Andelic, Forslund (25) concluded that studies mapping patterns of ABI service use within many different healthcare systems and countries are of “international interest” and are needed to facilitate ABI service planning and resource allocation.

Despite this, studies mapping patterns of service use and particularly, long-term service use in individuals who survive an ABI are still relatively rare. This is problematic as we know that individuals who have experienced a brain injury often need ongoing services from multiple services well beyond the early stages of recovery after ABI. In a French study, across a four-year period after discharge from an acute care setting, 78% of individuals had received physiotherapy, 61% had received speech/cognitive therapy, 50% had received occupational therapy, 41% had received psychological support, 63% had received specialized medical follow-up and only 21% had received support around reintegrating into society (22). In an Australian study, Hodgkinson, Veerabangsa (26) traced the trajectory of service use in individuals who survived a TBI from 6 months to 17 years postinjury. In this time, the mean number of services (medical, allied health professional, financial, vocational and educational and transport) used was 4.2. There was only a moderate decline in service use as a function of time. Somewhat conversely, in a recent study in Norway, Andelic, Forslund (25) demonstrated that there was a significant decrease in service use over time after a moderate-to-severe TBI. At a ten-year follow-up, physical therapy was the most frequently used service (16%) followed by speech and language therapy (3%) and occupational therapy (1%). Service use in a post-acute neurorehabilitation service has been mapped in an American cohort of survivors (26,27). These studies found that the most frequently used services were appointments with physicians, psychologists and social workers, occupational therapy and physical therapy (26,27). Among the least frequently used services provided by the ABI facility were group recreational programs and home health care. Around 14% of families did not avail of any post-acute rehabilitation services provided by the facility (26,27).

A number of studies have demonstrated that the pattern of service use after brain injury is linked to factors such as the severity of the brain injury, the level of cognitive and psychosocial disability, gender, pre-injury employment status and geographic factors (22,25,26). In an Irish context, the long-term pattern of service use in individuals who experienced moderate-to-severe ABI has yet to be determined.

Here, we aim to describe the clinical profile of individuals who experienced a moderate-to-severe ABI in Ireland, their longitudinal outcomes in the domains of mobility, return to work, independent living and ability to maintain key relationships and their patterns of self-reported service engagement over a seven-year period.

Materials and methods

Design

The study was longitudinal in design. Individuals who survived a moderate-to-severe ABI completed outcome assessments at one (t1) and seven years (t2) after completing a publicly funded inpatient post-acute neurorehabilitation program in Ireland.

Structure of ABI services in Ireland

There are two neuroscience hubs in Ireland, located in major public hospitals in large cities (Cork and Dublin). There is one public inpatient post-acute neurorehabilitation center in Ireland – The National Rehabilitation Hospital in Dublin (NRH). Some services along the care pathway are provided by or funded by the public health-care system (Health Service Executive; HSE) but many are provided by nonprofit organizations such as Headway, Acquired Brain Injury Ireland and Quest Brain Injury Services for community and longer-term care.

Participants in the current study were recruited from the NRH. The NRH is a publicly-funded post-acute neurorehabilitation center, accessible for those with moderate to severe acquired brain injuries between the ages of 18–70. Referrals to the NRH come from acute hospitals nationally and regionally. Participants are admitted for inpatient neurorehabilitation for periods generally ranging from 8 to 16 weeks. Significant waiting-lists exist for access to this service. Following discharge, the majority return to their local community, with a small number requiring further residential or nursing care.

Procedure

Participants who had taken part in standard psychological interventions that were provided on the brain injury program were invited to take part. Participants had all availed of a neurorehabilitation program in a post-acute hospital setting, with core input from physiotherapy, speech and language therapy, occupational therapy, medical social work, and psychology services. Psychological input for the cohort included individual and group psychology sessions. Upon completion of the tertiary neurorehabilitation program, some participants had access to outpatient and community rehabilitation services. Access to outpatient and community rehabilitation services was contingent on outstanding rehabilitation needs and goals as well as the availability of services within the patient's area and this varied on a case by case basis.

Participants were excluded from the study at t1 if they were under 18 years of age, if it was less than one year since the onset of their ABI, if they did not speak English as a first language, if their level of disability meant that they were unable to complete the measures, even with telephone support from the research team, or if their level of cognitive impairment meant that they were unable to give written informed consent.

One year post-discharge from inpatient neurorehabilitation (t1), information about the study was posted to all eligible participants. A member of the research team contacted them by telephone to discuss the study in more detail and to address any questions that they might have. Where individuals agreed to participate, they were asked to give verbal consent over the telephone and a consent form and the outcome measures were posted to them. Telephone support was offered in completing the questionnaires where individuals were experiencing cognitive, motor, language or visual difficulties. Participants were contacted by telephone a second time to facilitate the completion of the outcome measures. At seven years after accessing

post-acute neurorehabilitation services (t2), the individuals who participated at the one-year follow-up (t1) were contacted by letter to inform them that a second phase of the study would be taking place and that they would be contacted by telephone to discuss it further and to address any questions that they might have. The procedures for attaining written informed consent and for data collection at the seven-year follow-up were the same as those at the one-year follow-up. All participants gave written informed consent. The research study was approved by the Ethics Committees of the National Rehabilitation Hospital, Dublin and University College Dublin.

Participants

Participants comprised 45 adults with ABI who attended an inpatient post-acute neurorehabilitation program following a brain injury between 2010 and 2012 and who completed an outcome assessment at one-year after accessing the program (mean (M) = 1.25, standard deviation (SD) = 0.56; t1). The 45 participants included in the original sample had experienced TBI (35.6%), stroke (ischemic and hemorrhagic; 35.6.0%) or another form of ABI such as encephalitis, anoxic brain injury and brain tumors (28.9%). Although Glasgow Coma Scale data was not available for all participants, the criteria for admission to the inpatient post-acute neurorehabilitation program is the presence of a moderate or severe ABI, thus, all participants were classified as having a moderate-to-severe ABI based on alternate neurological measures (e.g. posttraumatic amnesia, length of loss of consciousness, length of coma, neurosurgical complications and interventions). On average, participants were 53.3 years of age. Participants spent, on average, 8 weeks at the inpatient post-acute setting, however, the length of hospital stay ranged from 2 to 19 weeks.

A second outcome assessment was conducted at seven-years after accessing the program ($m = 7.9$, $SD = 0.55$; t2). Between the one-year (t1) and seven-year (t2) follow-ups, 13 participants were lost to follow up. Of these 13 participants, five had died (38.46%), five (38.46%) did not consent to participate at t2 and a further three (23.07%) were not contactable by phone or letter at t2. Thus, the final sample for the longitudinal analyses comprised 32 adults with moderate-to-severe ABI (20 males). The 32 participants included in the final sample had experienced TBI (40.6%), stroke (25.0%) or another form of ABI (34.4%). On average, participants were 52.7 years, ranging from 27 to 76 years. Participants spent, on average, 8 weeks at the inpatient post-acute setting, however, the length of hospital stay ranged from 2 to 15 weeks. Participants had spent, on average, 14 years in education, with the length of education ranging from 8 to 22 years. Two participants (6.3%) reported having a psychiatric diagnosis prior to injury.

There were no significant differences in the demographic and clinical characteristics of those who completed the seven-year follow-up and those who were lost to follow-up between t1 and t2 (see Table 1; all $p > .01$). Although not statistically significant, it is noteworthy that a higher proportion of people who were lost to follow-up between t1 and t2 experienced a stroke compared to those who completed follow-up at t2 (see Table 1).

Outcome measures

Participants were asked to complete a *Sociodemographic and Support Questionnaire* at one- and seven-years after accessing post-acute neurorehabilitation services. The questionnaire was developed to assess participant's self-reported functioning in the domains of living independently, physical mobility (wheelchair use), ability to maintain relationships (marital and with children), employment status before injury, return to work after injury, source of income following injury and mental health history prior to injury. Participants were also asked to report the range of support services that they engaged with across three categories: "allied health professional services," "community services" and "other services." Allied health professional services included: physiotherapy, occupational therapy, psychology, and speech and language therapy. Community services reflected any service that was available via community organizations such as Headway, Acquired Brain Injury Ireland and Quest Brain Injury Services or Health Service Executive clinical services. As the services engaged with in the community could include allied health professionals services; there may be some overlap between the two categories. For example, an individual may have accessed physiotherapy via local Health Service Executive services and psychology via a community organization. Finally, participants were asked to indicate any "other services" that they accessed. As the service engagement questions were open-ended; some participants simply indicated whether they had accessed "community services" and "other services" (yes or no) while others provided more specific details about the services obtained.

Statistical analyses

Descriptive statistics, McNemar's tests, and marginal homogeneity tests were used to describe and compare outcomes in the domains of independent living, mobility, return to work and ability to maintain key marital and family relationships of individuals living with moderate-to-severe ABI at t1 and t2. Chi-Squared tests,

Table 1. Demographic and injury characteristics of adults who sustained a moderate-to-severe ABI who were included in the sample at the one- (t1) and seven-year (t2) follow-ups.

Demographic & Clinical Characteristics	Mean (SD) or n (%)		
	T1 follow-up (N = 45)	T2 follow-up (N = 32)	P-value
Gender			
Male	28 (62.2)	20 (62.5)	
Female	17 (37.8)	12 (37.5)	0.6 ¹
Years of Education (years; t2 only)	Not available	14 (12–18)	
Age (years)	53.34 (14.4)	52.7 (12.1)	0.7 ¹
Type of Injury			
TBI	16 (35.6)	13 (40.6)	
Stroke	16 (35.6)	8 (25.0)	
Other ABI	13 (28.9)	11 (34.4)	0.07 ²
Length of Hospital Admission (weeks)	8.08 (3.7)	8.3 (3.57)	0.6 ³
Employment Status Before ABI			
Employed	34 (75.6)	25 (78.1)	
Unemployed	11 (24.4)	7 (21.9)	0.4 ¹
Psychiatric History Prior to ABI (t2 only)			
Yes	Not available	2 (6.3)	
No	Not available	30 (93.8)	

¹Fishers Exact Test, ²Chi-Square Test, ³Independent Samples T-Test. The p-values reflect the comparison of the demographic characteristics of those who completed the seven-year follow-up (N = 32) and those who were lost to follow-up between t1 and t2 (N = 13).

Fisher's Exact tests, and Point Biserial Correlations were used, as appropriate, to test the associations between employment status at seven-years and key demographic and injury characteristics. Descriptive statistics and a series of McNemar's tests were also used to describe and compare self-reported service engagement at t1 and t2. Chi-Squared tests and Point Biserial Correlations were used to test the associations between demographic and injury characteristics and self-reported service engagement after ABI. In light of the anticipated number of statistical analyses – a more conservative alpha threshold ($p < .01$) was applied to reduce the probability of type 1 error.

Results

Outcomes of adults with ABI at a one- and seven-year follow-ups

At one-year following completion of post-acute neurorehabilitation program (t1), all 32 participants were living independently at home and continued to do so across the seven-year follow-up period (t2) with the exception of one person (3.1%) who transitioned to a supported living setting. At the one-year follow-up, most participants (87.5%) shared their home with a family member or a partner and only a minority were living alone (9.4%) or with a housemate (3.1%). These living arrangements did not change significantly across the seven-year follow-up period (see Table 2). With respect to marital status, at one year after accessing post-acute inpatient services, over half of the participants (62.5%) were married, a further 31.3% were single while, a minority were separated (3.1%) or divorced (3.1%). There was minimal variation in relationship status over time with only two participants experiencing marital

Table 2. Outcomes in adults who sustained a moderate-to-severe ABI at a one- and seven-year year follow-ups.

Demographic characteristics	N (%)		p-value
	t1	t2	
Marital Status			
Married	20 (62.5)	18 (56.3)	
Single	10 (31.3)	10 (31.3)	
Separated	1 (3.1)	2 (6.3)	
Divorced	1 (3.1)	2 (6.3)	
Widowed	0		0.096
Living Arrangements			
Independently at home	32 (100)	31 (96.9)	1.00
Supported Living Setting	0	1 (3.1)	
Living With			
Living Alone	3 (9.4)	5 (18.6)	
Living with Family or a Partner	28 (87.5)	27 (84.4)	
Living with other (e.g. housemate)	1 (3.1)	0	
Wheelchair Use (t2 only)			
No Wheelchair Use		26 (81.3)	
Wheelchair Dependent		1 (3.1)	
Somewhat Wheelchair Dependent		5 (15.6)	
Contact with Children (t2 only)			
Contact with Children		24 (75%)	
No Contact with Children		8 (25%)	
Return to Work Post ABI			
Employed	5 (15.6)	11 (34.4)	
Unemployed	27 (84.4)	21 (65.6)	0.03
Source of Income Post ABI (t2 only)			
Wages/Salary		8 (25)	
Disability Allowance		14 (43.8)	
Pension		7 (21.9)	
Other/Combination		3 (9.4)	

breakdown (separation or divorce) in the interval between the one- and seven-year follow-ups (See Table 2). At seven years after accessing post-acute inpatient services, three quarters of adults living with an ABI (75%) reported having children with whom they were in contact. At the same time point, most participants (81.3%) were physically mobile, one (3.1%) person was wheelchair dependent, and a further five (15.6%) were somewhat wheelchair dependent.

Prior to injury, over three quarters of the participants (78.1%) were employed (see Table 1). Following ABI, the rates of return to work were low. While only five people living with an ABI (15.6%) had returned to work at one-year after accessing post-acute inpatient services, 11 had returned to work by the seven-year follow-up (34.4%). Given the low rate of return to work following injury, it is unsurprising that at the seven-year follow-up, a state-funded disability allowance was the main source of income for almost half of the participants (43.8%). A further 25% of participants were in receipt of wages/salary, 21.9% had a pension and the remaining 9.4% of the participants described their income as being drawn from 'other' sources or a combination of sources.

Return to work at seven years following completion of a post-acute neurorehabilitation program was not associated with age, gender, mobility, years of education, or the type of ABI experienced (all $p > .01$).

Self-reported service use in adults with ABI in Ireland at a one- and seven-year follow-ups

At the one-year (t1) and seven-year (t2) follow-ups, participants were asked to report the range of support services that they had accessed. At t1 in terms of allied health professional services, the highest proportion of participants ($N = 20$; 62.5%) had engaged with occupational therapy. This was followed by physiotherapy; with 15 (46.9%) participants accessing the service. At the same time point, one third of participants ($N = 12$; 37.5%) had engaged with psychology and less than one fifth had accessed speech and language therapy ($N = 5$; 15.6%).

As the service engagement questions were open-ended, some participants indicated whether they had availed of "community services" and "other services" (yes/no) while others provided additional details about types of the services that they had accessed. While there were not enough data available to merit descriptive statistics of the types of services accessed within the categories of "community services" and "other services" some are listed to give a flavor of the range of supports accessed.

At the one-year follow-up, over 65% of participants ($N = 21$) had engaged with support services available through community organizations such as Headway, Acquired Brain Injury Ireland and Quest Brain Injury Services. The services accessed through these community organizations included counseling services, psychology, occupational therapy, group therapy, support with activities such as shopping, managing the home, managing finances, support building computer and communication skills as well as support around engaging with leisure activities such as gardening, flower arranging and creative design. One half of

participants ($N = 16$; 50%) had accessed "other services." These included specialist services and community supports such as mental health services, neurology, immunology, ophthalmology, respite care, home help, and personal assistant hours that were funded through the HSE. At t1, one fifth of participants ($N = 7$; 21.9%) reported an ongoing involvement with the post-acute neurorehabilitation service.

The data collected around service engagement at the seven-year follow-up reflects the support services accessed across the entire seven-year window and does not adjudicate between those accessed prior to- and after the one-year follow-up (t1). As Table 3 shows, there were no marked changes in self-reported service engagement between the one- and seven-year follow-ups. That is, in terms of the allied health professional services, the proportion of participants who reported availing of speech and language therapy, occupational therapy, physiotherapy, and psychology did not change between the one- and seven-year follow-ups (see Table 3).

The proportion of participants reporting engaging with services available through community organizations and "other services" also did not change across the seven-year follow-up period. Finally, the proportion of participants who reported an ongoing involvement with the post-acute neurorehabilitation services also did not change over time with only two new participants re-accessing this earlier level service in the interval between the one- and seven-year follow-ups (See Table 3).

At t2, over 69% ($N = 22$) of participants had engaged with two or more allied health professional services. A further 18.2% ($N = 6$) of participants had engaged with one service while, the remaining 12.6% ($N = 4$) did not engage with any allied health professional service by the seven-year follow-up.

Table 3. Support services accessed by adults who sustained a moderate-to-severe ABI at a one- and seven-year follow-ups.

Service Use	N (%)	t1	t2	p-value
Ongoing Involvement with Post-Acute Services				
Yes	7 (21.9)	9 (28.1)		
No	25 (78.1)	23 (71.9)		0.5
Services in Community				
Yes	21 (65.6)	24 (75)		
No	11 (34.4)	8 (25)		0.38
Psychology				
Yes	12 (37.5)	14 (43.8)		
No	20 (62.5)	18 (56.3)		0.5
Occupational Therapy				
Yes	20 (62.5)	19 (59.4)		
No	12 (37.5)	13 (40.6)		1.0
Speech & Language Therapy				
Yes	5 (15.6)	12 (37.5)		
No	27 (84.4)	20 (62.5)		0.016
Physiotherapy				
Yes	15 (46.9)	19 (59.4)		
No	17 (53.1)	13 (40.6)		0.29
Other Services				
Yes	16 (50)	17 (53.1)		
No	16 (50)	15 (46.9)		1

The data collected around service use at t2 reflects the support services accessed across the entire seven-year window following completion of a post-acute neurorehabilitation program and does not adjudicate between those accessed to prior to-and after the one-year follow-up (t1).

Relationship between demographic and injury characteristics and self-reported service engagement at a seven-year follow-up

Participants were divided into two groups based on the number of allied health professional services that they reported engaging with (<2 and 2+ allied health services). Point-Biserial Correlations and Chi-Squared Tests were used to test the associations between the demographic and injury variables and self-reported service engagement at t2. Engagement with two or more allied health professional services, with services available through community organizations, and “other services” at t2 was not associated with age, years of education, gender or the type of ABI experienced (all $p > .01$).

Discussion

Here, we provide demographic and injury characteristic data for individuals who survived a moderate-to-severe ABI in Ireland. We describe longitudinal outcomes after ABI in the domains of independent living, mobility, ability to maintain key relationships and return to work. We also report patterns of self-reported service engagement across a seven-year follow-up period.

Similar to findings from other longitudinal studies, all participants in our study were living independently and 63% were in a marital relationship at the one year follow-up (1,5,7). With the exception of one participant, all participants were able to maintain their independence across the seven-year follow-up period. Two marriages ended in the interval between the t1 and t2 outcome assessments. Mobility outcomes were positive with over 81% of participants reporting no wheelchair use at t2. It has long been acknowledged in the literature that families play a vital role in supporting family members through the rehabilitation process following ABI and often transition into a caregiver role once the person is discharged from acute and post-acute rehabilitation services (28,29). Consistent with this, we found that approximately 85% of participants lived with their family or partner at one and seven years following completion of a post-acute neurorehabilitation program. With this in mind, ABI service providers may want to consider the ongoing and evolving needs of family members at all phases of rehabilitation but especially over the longer-term when the person is living in the community (28).

The rates of return to work following ABI were low, with only 34% of people returning to work at the seven-year follow-up, consistent with other studies (1,4,11). While a number of longitudinal studies (1,7) have shown that the rates of return to work remain stable or decline with time after injury, we found that there was a trend toward an increase in the number of participants employed at seven-years after completion of a post-acute neurorehabilitation program (34%) compared to t1 (16%). These differences across studies may at least, in part, be explained by variation in the age and severity of participant’s injuries, as well as in the length of the follow-up period (1,7). While, key studies in the area suggest that return to work may be associated with demographic and injury characteristics, we observed no such associations in our data (2,14–16). It is important to note that the outcomes we observed

across the domains of independent living, mobility, relationships and return to work are at least, in part, a product of our methodological approach. Like many studies in the area, we took a quantitative approach and measured the rates of independent living, mobility, separation/divorce and return to work. While, these data give us some insight into outcomes in these domains they do not capture the complexity of the person’s lived experience. For example, while a couple may remain married, they may be experiencing difficulties associated with the sequelae of the brain injury (9). Further qualitative research exploring whether specific aspects of the sequelae of the ABI contribute to individual’s difficulties with interpersonal relations (e.g. poor perspective taking, poor inhibition, and emotional lability) would be beneficial.

In an Irish context, we show that in terms of allied health professional services, individuals who sustained a moderate-to-severe ABI reported most frequently engaging with occupational therapy and physiotherapy, followed by psychology and speech and language therapy over the seven-year period. At the seven-year follow-up, approximately three quarters of participants had accessed two or more allied health professional services and services available through Health Service Executive services and community organizations such as Headway, Acquired Brain Injury Ireland, and Quest Brain Injury Services Support services accessed through community organizations included psychological support, occupational therapy, support with activities of daily living and leisure activities as well as support with skill-building. During this same time period, half of the participants had also accessed “other services” including outpatient services, respite care, home help, and personal assistant. One fifth of participants reported an ongoing involvement with the post-acute neurorehabilitation service at seven years after the inpatient stay with two participants re-accessing this earlier level service in the interval between the one- and seven-year follow-up. Interestingly, there were no significant changes in self-reported service engagement across the seven-year follow-up period.

Only a handful of other studies have mapped the pattern of service engagement in individuals who have survived an ABI (17,22,25,26,30). Comparisons between our study and these studies are limited by methodological differences, such as the stage at which participants were at along the continuum of care and the structure of the healthcare systems through which participants accessed services. However, the rates of engagement with allied health professional services in our study over a seven-year period after discharge from post-acute services were similar to those observed in a French study that was carried out over a four year period after discharge from an acute setting (22). The rates of engagement with occupational therapy and speech and language therapy that we observed at the seven-year follow-up were considerably higher than those observed in a Norwegian sample at a ten-year follow by (25).

Our ability to interpret the pattern of service engagement in the individuals who sustained an ABI is limited by the fact that we did not ask participants to specify the point in their rehabilitation at which they accessed a particular service or whether

the service formed part of public, nonprofit or private services. We also did not ask them if they were able to access the level of service that they needed at a particular time or whether they experienced any barriers in accessing services (e.g. financial issues, lack of access to services due to geographical location, long waiting lists, lack of awareness or knowledge about brain injury and ABI services, mobility, accessibility, transport, needs not matching service availability, lack of access due to age restrictions). Future research should explore possible barriers to ABI service engagement in Ireland and internationally.

Although ABI services in Ireland provide intensive support in the first two years postinjury in acute and sub-acute settings; there are considerably fewer support services available over the longer-term in an outpatient capacity. Our study tentatively suggests that there is a persistent and high level of service need in this population; with 69% of survivors engaging with two or more allied health professional services and 75% engaging with services in the community across the seven-year period. As many of our participants were young and middle-aged adults at the time of injury they may continue to live in the community for decades with some level of disability. Our findings tentatively call for more support services to be made available over the longer-term in an outpatient capacity such that they are available to aging survivors of ABI when they are needed.

Our study has a number of limitations that merit consideration when making inferences from our findings. Firstly, the scope of our study was narrow in that it only speaks to longitudinal self-reported service engagement and outcomes across the domains of independent living, mobility, and ability to maintain key relationships and return to work in individuals who sustained a moderate-to-severe ABI and who received inpatient post-acute rehabilitation services in Ireland. Although our sample size is in keeping with published quantitative studies in the area (17,30), it is nonetheless small and reflects a specific cohort of survivors of ABI in Ireland. Our findings cannot be generalized to those who experienced a mild ABI who would not have had access to the tertiary neurorehabilitation service or those with very severe ABI who were unable to take part in our follow-up study due to the level of cognitive and/or communication impairments. Our exclusion criteria meant that individuals who were unable to complete the questionnaire due to their level of disability, who did not speak English as a first language or who were in inappropriate placements such as nursing homes due to shortage of residential rehabilitation services in the community were not included in this study. Thus, our study also does not capture the outcomes and pattern of self-reported service engagement of these people living with ABI who may have even greater or more specific needs than our cohort (see 23 for a discussion of the unique challenges faced by young adults inappropriately placed in nursing homes). Furthermore, as a highly limited resource, access to specialist rehabilitation services in Ireland is limited. Thus, it is possible that those who did not receive inpatient post-acute care may have been offered fewer services and may be even less likely to have been linked in with longer-term supports in the community. More generally speaking, our findings are based on self-report by those who had an ABI, who may be lacking in awareness into their outcomes or be experiencing memory difficulties that impact upon their ability

to recall the services that they have engaged with over the years. While it may have been useful to obtain collateral information from close informants; it has been shown that those with a moderate-to-severe ABI are as accurate as informants in reporting injury-related changes in functioning over extended periods of time (31). The outcome data is based on self-reported functioning and we did not include standardized measures of functional outcomes or activities of daily living. Future longitudinal research could include standardized measures of functional outcomes to strengthen the findings.

As outlined above, key health policy documents (32,33) along with Burke et al. (18) have highlighted that among the many challenges facing the delivery of neuro-rehabilitation services in Ireland is the lack of reliable data that is available on the ABI population, particularly around the number of people who need neuro-rehabilitation services in Ireland. Without this type of information it is difficult to predict the levels of service need in Ireland and/or to advocate for the requisite funding and resources to meet the demand (18). Here, we begin to address this “data challenge” by providing some demographic and injury characteristic data for individuals who survived a moderate-to-severe ABI in Ireland. We provide a snapshot of longitudinal outcomes in the domains of independent living, mobility, and ability to maintain key relationships and return to work and self-reported service engagement in this cohort. Despite the limitations associated with our study, it is hoped that these data will generate a more detailed understanding of the service needs of individuals living with ABI and their families in Ireland and help to guide future service planning and delivery in both Ireland and internationally.

The literature would benefit from a prospective longitudinal study of service engagement and barriers to use of same in a heterogeneous representative cohort of individuals who sustained an ABI across a 20- to 30-year follow-up period. In a larger more representative sample, it would also be interesting to compare longitudinal outcomes and service engagement in individuals who experienced different types of ABI (e.g. TBI versus stroke and discrete/focal v diffuse injuries). Here, we did not have the data to reliably explore the relationship between self-reported service engagement and long-term outcomes for people living with ABI. However, data examining the impact of engaging with neuro-rehabilitation services upon outcomes assessed using internationally validated measurement tools will be critical for advocacy, policy development, and evidence-based service planning and delivery for the ABI population (18).

Conclusions

In a cohort of individuals who survived a moderate-to-severe ABI in Ireland, there was minimal variation in outcomes in the domains of independent living, mobility, ability to maintain key relationships and return to work across a seven-year follow-up period. There may be a persistent and high level of service need in this population in the years that follow injury. As many individuals who survive ABI are young and middle-aged adults at the time of injury they may continue to live in the community for decades with some level of disability. While ABI services in Ireland provide intensive support in the first two years postinjury in acute and sub-acute settings; our

findings tentatively call for more support services to be made available over the longer-term in an outpatient capacity and within the wider community. Additional resources may need to be allocated to outpatient and community ABI services in order to meet the ongoing and evolving needs of those living with an ABI over the longer-term.

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