ORIGINAL ARTICLE

Predictors of Follow-Up Completeness in Longitudinal Research on Traumatic Brain Injury: Findings From the National Institute on Disability and Rehabilitation Research Traumatic Brain Injury Model Systems Program

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Abstract

Objective: To identify baseline participant variables in the domains of demographics, medical/psychosocial history, injury characteristics, and postinjury functional status associated with longitudinal follow-up completeness in persons with traumatic brain injury (TBI) using the TBI Model Systems (TBIMS) National Database (NDB).

Design: Exhaustive chi-square automatic interaction detection was used to identify factors that classified participants according to level of follow-up completeness.

Setting: Retrospective analysis of a multi-center longitudinal database.

Participants: Individuals (N=8249) enrolled in the TBIMS NDB between 1989 and 2009 who were eligible for at least the first (year 1) follow-up up to the fifth (year 15) follow-up.

Interventions: None.

Main Outcome Measures: Follow-up completeness as defined by 6 different longitudinal response patterns (LRPs): completing all follow-ups, wave nonresponse, dropping out, completing no follow-ups without formally withdrawing, formally withdrawing before completing any follow-ups, and formally withdrawing after completing some follow-ups.

Results: Completing all follow-ups was associated with higher levels of education, living with parents or others, and having acute care payer data entered in the NDB. Subgroups more vulnerable to loss to follow-up (LTFU) included those with less education, racial/ethnic minority backgrounds, those with better motor functioning on rehabilitation discharge, and those for whom baseline data on education, employment, and acute care payer were not collected. No subgroups were found to be more likely to have the LRPs of dropping out or formal withdrawal.

Conclusions: These data identify subgroups in which retention strategies beyond those most commonly used might reduce LTFU in longitudinal studies of persons with TBI, such as the TBIMS, and suggest future investigations into factors associated with missing baseline data.

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Longitudinal studies are vital to understanding long-term outcomes after traumatic brain injury (TBI). However, 33% to 50% of participants in these studies have historically been lost to follow-up (LTFU).[1,2] Participants who are lost nearly always differ systematically from those retained,[1,2] which threatens both the internal and external validity of longitudinal outcome studies[3] and promotes

biased conclusions about outcomes after TBI. Indeed, factors generally predictive of LTFU (eg, low socioeconomic status [SES]) often adversely affect outcomes,[4] which suggests that systematic LTFU might yield outcome data that are positively biased.

Such bias can be reduced by preventing LTFU (eg, by increasing the frequency of participant contact or using sophisticated tracking systems[5,6]) or by using statistical methods that compensate for loss after it has occurred. However, statistical procedures cannot always reliably estimate or eliminate the impact of LTFU on outcome data.[7] Prevention techniques are, therefore, more desirable[1] but require what Greenland[8] termed subject matter knowledge, such as data regarding which participants are more vulnerable to LTFU.

Relatively few investigations have focused on factors predictive of LTFU in longitudinal studies of individuals with TBI. A study by Corrigan et al[1] suggested that those with a history of substance abuse, with higher motor function at rehabilitation discharge, and from "socioeconomically disadvantaged groups" (racial and ethnic minorities and those who had little education, were unemployed at time of injury, or were dependent on public funding for acute care) were more frequently lost at 1 and 2 year postinjury follow-ups in 3 large longitudinal studies.

Of the 3 datasets analyzed by Corrigan, the TBI Model Systems (TBIMS) National Database (NDB) includes the largest number of participants, is the longest running, and has provided the basis for the most analyses, yielding approximately 350 published studies thus far.[9] The NDB has experienced LTFU since its inception, as do all longitudinal studies, and instituted targets for follow-up completeness in 2006.[10] However, between 17% and 23% of participants in the NDB are still lost depending on the specific follow-up point.[11]

The goal of the current study was to determine participant-related factors predictive of LTFU in the longitudinal study of persons with TBI using the current TBIMS NDB. Previous work in this area has sought to identify factors associated with either response or nonresponse at 1 or 2 follow-ups, but we aimed to identify factors associated with a number of different longitudinal response patterns (LRPs) (eg, completing all follow-ups, skipping some follow-ups) up to a maximum of 5 follow-ups. This approach allowed us to investigate factors associated with LTFU across the more lengthy sequence of follow-ups needed to best characterize long-term outcomes, thus enhancing the potential usefulness of our findings.

The NDB was ideal for our purposes because of the large number of available participants, volume of data collected, and number of follow-up data points available, all of which suggest that findings in the NDB would be applicable to many other longitudinal studies of persons with TBI and could inform follow-up practices to maximize participant retention. In addition, there is value in identifying factors associated with LTFU in the NDB for its own sake because of its significant contribution to the outcomes

literature, evidence of selective LTFU[1,12] in the database, and the association between previously established predictors of LTFU in the NDB and outcomes.[13-15]

The overarching goal of the present study was to determine whether various LRPs could be predicted early in study participation and to identify participant characteristics that might signal the need for implementation of specific longitudinal retention strategies. Ideally, these strategies would maximize retention and, therefore, enhance the validity and applicability of longitudinal studies of persons with TBI.

Methods

TBI Model Systems

An extensive description of the TBIMS and its NDB is reported in Dijkers et al.[10] Further information regarding inclusion criteria and data included in the NDB is available on the TBMIS National Data and Statistics Center website.[11] Briefly, participants must have sustained a moderate-severe TBI as evidenced by a Glasgow Coma Scale score of <13 in the emergency department, loss of consciousness >30 minutes, posttraumatic amnesia (PTA) >24 hours, and/or structural abnormalities indicative of TBI on neuroimaging; must be ≥16 years old; and must have received acute care and rehabilitation from a participating medical center. Informed consent is obtained from the participant or, if unable, a family member or legal guardian.

Data collected just prior to rehabilitation discharge (baseline) include case mix, acute care, and rehabilitation information obtained through review of emergency and acute care medical records and an interview with the participant or proxy if the participant is unable to respond reliably. Review of rehabilitation records is used to calculate scores on functional status measures (eg, FIM[16] and Disability Rating Scale[17]). Follow-up data on outcomes are currently collected 1, 2, 5, and 10 years postinjury and every fifth year thereafter. The follow-up survey is completed in-person or via telephone or mail with the participant or a proxy if the participant is unable to respond.

Analyzed sample

At the time of our analyses, the NDB included 9310 participants enrolled at 22 centers that are currently (16 centers) or previously (6 centers) participating in the TBIMS. Participants whose LRP, which will be subsequently discussed, could not be determined from the data were excluded from the analysis. These included participants whose first (year 1) follow-up was not yet due (n=589) and those incarcerated during ≥1 follow-ups (n=251) because incarcerated participants are not contacted. Participants who died before completing any follow-ups (n=207) were also excluded. Only 14 participants were eligible for follow-up at year 20 and were also excluded. The sample analyzed included all individuals enrolled in the TBIMS between 1989 and 2009 and who were eligible for at least the first (year 1) follow-up up to the fifth (year 15) follow-up (N=8249).

Longitudinal response pattern

LRP was the outcome variable in our analyses. Table 1 contains numbers and examples of each LRP included as a possible

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List of abbreviations:

CHAID	chi-square automatic interaction detection
HS	high school
LRP	longitudinal response pattern
LTFU	loss to follow-up
NDB	National Database
PTA	posttraumatic amnesia
SES	socioeconomic status
TBI	traumatic brain injury
TBIMS	Traumatic Brain Injury Model Systems