

Assessing life expectancy in brain
and spinal cord injuries:
the problem with US data

APIL Damages Special Interest
Meeting

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What I want to do in this session ...

- Persuade you that the maths are easy
 - ... in theory ...
- Mention three areas where things can go wrong
 - ... with examples ...
- Give you a hand-out that I hope will be a useful reference document

The maths

26 in group

1 death

Mortality rate is $1 \div 26 = 0.038462$

What can go wrong?

- Define 'the 26'
- Identify 'the 1'

Deaths

- Easier for smaller groups
- Harder for larger groups
- Harder when you don't "own" the group

Examples – Australia

SCI

... a complete database to the NDI, 15 separate files were obtained ...

... each of these files represents possible matches based on requiring matching of different combinations of data fields...

... each pair of records that are compared receives a weight that reflects the quality of the match: the higher the weight, the higher the 'quality' ...

... the NDI proposed follow-up with a clerical review ... from the likely matches ... there were no additional deaths to those already known and recorded in the database.

Middleton et al (2012)

'Life expectancy after spinal cord injury: a 50-year study' *Spinal Cord* **50** pp 803-11

Examples - USA

“... the staff of the NSCISC checked on the survival status of persons in the database by searching the Social Security Death Index online at www.ancestry.com.

... Persons not reported as deceased by the Model Systems and not found in the Index were assumed alive on June 15, 2011.

... The Social Security Death Index has previously been found to be 92.4% sensitive and 99.5% specific for persons in the NSCISC database [ref. 20]...

... That these values are not each 100% implies that, on balance, the mortality rates calculated here may be slight underestimates and the life expectancies are slight overestimates.”

Shavelle et al. (2015)

‘Mobility, continence, and life expectancy in persons with ASIA impairment scale grade D spinal cord injuries’, *Am. J. Phys. Med. Rehabil.* **94** pp. 180-191

Accuracy of SSDI

- **Ref 20:-**

“Almost 87% of deceased persons ages 50+ were found, 69.8% of persons ages 30–49 and 34.6% of persons younger than age 30. Other factors influencing the likelihood of finding deceased persons in the SSDI were male gender, white race, being married, knowing the Social Security number and survival of 1+ years post-injury”

DeVivo et al (2004)

‘Accuracy of world-wide-web death searches for persons with traumatic brain injury’,
Brain Injury, **18** pp. 1155-1162

Accuracy of SSDI (cont)

- **Ref 20:-**

“In conclusion, the SSDI can provide useful information for mortality studies among persons with TBI.

... however, it does a poor job of identifying deaths among younger persons.

... sole reliance on the SSDI may result in significant under-ascertainment of mortality and over-estimation of life expectancy.

... moreover, the measured effect of mortality risk factors such as age, gender and marital status would also be biased based on the differential likelihood of inclusion in the SSDI. These issues need to be considered and understood when interpreting results of future published TBI mortality studies from the US that rely in whole or part on use of the SSDI for ascertainment of survival status.

... these results also underscore the importance of evaluating the quality of secondary data sources before incorporating them in ongoing studies.”

Accuracy of SSDI (cont)

“The results for men are ... the WWW ... identified up to 94.7% of ... NDI deaths.

The results ... for women are ...[that] the WWW agreed on only ... 31.1% of ... NDI deaths. “

Sesso et al (2000)

‘Comparison of National Death Index and World Wide Web death searches’

Am J Epidemiol **152** 107-111

Lessons ...

- The SSI is a cheap and cheerful solution
- But is inaccurate for several groups – younger people, women, etc.
- Implies too few deaths and hence mortality is too light
- Questions comparisons of male and female experience.

TBI

- “Men were three times more likely to die than women”

Harrison-Felix et al (2009). Mortality over four decades after traumatic brain injury rehabilitation: a retrospective cohort study.

Arch Phys Med Rehabil, **90**, pp. 1506-13.

- Are they?
- If (virtually) all male deaths identified, and only 31% of female deaths, then ratio is not 3-1 but 3-3

Lost to follow-up

- Inevitable that the researchers lose track of some subjects
- How many?
- How are they treated in the analysis?

Back to 'the 26'

- Is our group of 26 a sample of a population of interest?
- Is it a sample looking for a population?
- Is it an appropriate, unbiased sample from the population?

- “A member of one population cannot be included in a sample to represent another population unless he is also a member of that population. The evidence of this truth is so fundamental that it should not be necessary to lay emphasis on it.”

Reichmann WJ (1961) *Use and Abuse of Statistics* London, Pelican Books

What to expect

- An explanation of how the sample was taken from the population

Databases - US

- California Department of Developmental Services
- Traumatic Brain Injury Model Systems
- Spinal Cord Injury Model Systems

Example - CDDS

- Importance of degrees of 'rolling and sitting'
- This entire category of mobility was dropped by CDDS in 2005
- Where now for CP research?

TBIMS – Study Limitations

- Only includes moderate to severe TBI victims (“PTA>24 hrs or LOC>30 minutes or GCS in ED<13 or intracranial neuroimaging abnormalities”)

Their Own Comments:

- “Lack of control or comparison group
- Lack of uniformity in treatment across all Centers
- Attrition in follow-up
- Inability to systematically track post-acute service utilization
- Limited follow-up evaluations if Center defunded”

SCI – Study Limitations

- Major concern is ‘lost to follow-up’
 - 18% after 1 year
 - 43% after 5 years
 - 67% after 15 years

Comparison with control group

- By definition – UK general population
- By default – US general population
- Ensure consistency between study period and population mortality table used
 - E.g. Shavelle et al letter questioning the Middleton et al study – they used Australia Life Table 2005-2007 where the study covered the period 1955-2006: median period 1995-1997

Thank you

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