



Disaggregation of mortality data by disability status and measurement challenges

Mortality section
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Measurement challenges

- Definitional issues:
 - What condition, and how severe: physical, mental and functional impairments
 - How is it assessed: self-report or proxy reporting, subjective vs. clinical diagnostic, etc.
- At the population-level, disability is a rare condition
 - Only census and potentially administrative registers provide full population coverage
 - Surveys focusing on households with members experiencing impairments depend on relevant sampling frame derived from the most recent census (or registers)

Challenges to measure causes of death and disability status

- Information on causes of death is known only for about 1/3 of countries with good vital registration
- For the rest of the world knowledge about causes of death is only known thru verbal autopsies collected only for some population samples or indirectly thru proxy (i.e., statistical modelling using covariates)
- By default, disability status of the deceased person is not collected in vital registration or verbal autopsies

SDG target 3.2 on child mortality

- Children disability status: from what age, what conditions and based on what assessment method, and who is reporting?
- Can we measure child mortality by disability status?
 - The Division for Social Policy and Development on behalf of the UN Secretariat for the convention on the rights of persons with disabilities asked the UN Interagency Group on Child Mortality – Technical Advisory Group (Washington D.C., 7-9 Dec. 2015)
 - UN IGME TAG 2015 consensus:
 - Clinically very difficult for newborns except for specific congenital conditions, and potentially possible only for children old enough to be diagnosed for various other conditions
 - In term of data sources, potentially only possible thru the use of registries or cohort studies especially designed for this purpose, or large enough to have the necessary statistical power
 - Currently beyond the scope of UN IGME due to lack of data, and other pending methodological and data priorities

Institutional vs. household settings

- Institutional settings should have administrative records allowing longitudinal analysis and in-depth investigations – including easier record linkages through potentially unique IDs or better quality recording of individual characteristics and clinical conditions.
- Household settings: more challenging situation requiring special enquiries or record linkage studies

Analytical issues with multi-dimensional disaggregation

- Frequent insufficient data disaggregation for small populations
- Issues of privacy and confidentiality (UNICEF, UNESCO, etc., use at least $n=25+$ unweighted observations for statistical disclosure in tabulations)
- Issues of sampling variance and random variations

Recommended analytical strategy to deal with small populations

- Need to produce and use standard errors for confidence intervals when interpreting and displaying survey results to assess if changes or differences between groups are statistically significant
- For rare events/conditions, increase time period for sufficient number of person-years of observation (e.g., 3/5 or 10 year moving window)
- Increase sampling size, or preferably use targeted sampling and follow-up surveys for more in-depth investigation

Count data vs. rates and ratios

Rates and ratios based on same source of data (e.g., survey) or different data sources (e.g., admin. data and census):

- If based on different data sources, potential issues with numerator vs. denominators: problem of matching statistical concepts and measurements, potential biases with differential reporting/selection between num./denom. For example:
 - Infant mortality by race/ethnicity in USA: deaths classified according to information provided by doctors or medical examiners tend to be mostly white or black, whereas births classified by information provided by mothers or families tend to be much more highly differentiated, with the result that the IMR estimates by race/ethnicity have sometimes grossly over- or under-estimated the true differences between social groups.
 - Mortality by occupation in Australia or by ethnicity in New Zealand: different ways in which occupation/ethnicity is recorded on death certificates and on census forms

Solutions to deal with numerator vs. denominator problems between data sources

Strategy #1. Cohort studies, confidential inquiries and HDSS

Prospective cohort studies

- Atlanta (United States): population-based 1985-87 cohort of 10-year-old children with development disabilities followed up for mortality and cause of death information using National Death Index to identify all deaths among cohort members during the follow-up period (1985–95)
 - Decoufflé, P., & Autry, A. (2002). Increased mortality in children and adolescents with developmental disabilities. *Paediatric and perinatal epidemiology*, 16(4), 375-382.
- Leicestershire Learning Disability Register (UK): a 13-year open cohort of 2436 adults with intellectual disability who are living in Leicestershire (including the city of Leicester) and Rutland (UK) and 409 deaths information between 1993-2005 from the Office for National Statistics (ONS)
 - Tyrer et al. (2007). Mortality in adults with moderate to profound intellectual disability: a population-based study. *Journal of Intellectual Disability Research*, 51(7), 520-527.
 - Tyrer, F., & McGrother, C. (2009). Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *Journal of Intellectual Disability Research*, 53(11), 898-904.
- Sweden: a 1955/59-1967 nationwide mortality follow-up study of 12,903 institutionalized mentally deficient subjects (children and adults)
 - Forssman et al. (1970). Mortality of the mentally deficient: a study of 12,903 institutionalised subjects. *Journal of Intellectual Disability Research*, 14(4), 276-294.
- Finland: a nationwide 35-year follow-up study of the life expectancy of people with intellectual disability (2366 subjects age 2-64 years in 1962)
 - Patja et al. (2000). Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of intellectual disability research*, 44(5), 591-599.
- WHO Study on global AGEing and adult health (SAGE), waves 0-3 (<http://www.who.int/healthinfo/sage/en/>): longitudinal study collecting data on adults aged 50 years and older, plus a smaller comparison sample of adults aged 18–49 years, from nationally representative samples in China, Ghana, India, Mexico, Russian Federation and South Africa
- Global Ageing Surveys and harmonized public use data (<https://g2aging.org/>) for 30+ countries: HRS (United States), MHAS (Mexico), ELSA (England), SHARE (20+ European Countries and Israel), CRELES (Costa Rica), KLoSA (Korea), JSTAR (Japan), TILDA (Ireland), CHARLS (China), LASI (India), IFLS (Indonesia)

Strategy #1. Cohort studies, confidential inquiries and HDSS

Confidential Inquiries to detect areas of deficiency in clinical practice and devise recommendations to resolve them

- Five Primary Care Trust areas of southwest England: review of the deaths of 247 people with intellectual disabilities aged 4 years and older registered with a general practitioner, who died in 2010-12. Investigators established a network to notify them of all deaths of people with intellectual disabilities, which included health, social-care, and voluntary-sector services; community contacts; and statutory agencies. Additional checks were made with GPs, prisons, community groups and leaders, development workers in minority ethnic communities, and services supporting people with intellectual disabilities to ensure that all eligible deaths had been reported.
 - Heslop et al. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*, 383(9920), 889-895.
 - Heslop, P., & Glover, G. (2015). Mortality of people with intellectual disabilities in England: a comparison of data from existing sources. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 414-422.
 - Glover, G., & Emerson, E. (2013). Estimating how many deaths of people with learning disabilities in England could be prevented by better medical care. *Tizard Learning Disability Review*, 18(3), 146-149.
- Ireland National Intellectual Disability Database (n=25,000): review of the deaths of 1115 subjects who died in 1995-2001. Data are completed by service providers, and collected annually from each separate health board region for all people with an intellectual disability in Ireland.
 - Lavin et al. (2006). Age at death of people with an intellectual disability in Ireland. *Journal of Intellectual Disabilities*, 10(2), 155-164.

INDEPTH Health and Demographic Surveillance Sites

- WHO Study on global AGEing and adult health (SAGE) wave 1, 2007 (<http://www.who.int/healthinfo/sage/indepth/en/>): Bangladesh (Matlab, n=4037), Ghana (Navrongo, n=4584), India (Vadu, n=5430), Kenya (Nairobi, n=2072), Indonesia (Purworejo, n=12395), South Africa (Agincourt, n=4085), UR of Tanzania (Ifakara, n=5131), Viet Nam (Filabavi, n=8535)
 - Kowal et al. (2010). Ageing and adult health status in eight lower-income countries: the INDEPTH WHO-SAGE collaboration. *Global health action*, 3(1), 5302.
 - Gómez-Olivé et al. (2014). Social conditions and disability related to the mortality of older people in rural South Africa. *International journal of epidemiology*, 43(5), 1531-1541.

Strategy #2. Unit-record linkage

Deterministic or probabilistic record linkage between 2 or more data sources with at least 1 providing impairment status

- A. Administrative and population registers, including health records
- B. Census and vital registration, including virtual cohorts linking multiple rounds of censuses, annual vital registration records and potentially additional administrative records (education, health, social benefits, employment, etc.)
 - Whole population:
 - **New Zealand Census Mortality Study (NZCMS)** anonymously and probabilistically links all census (1981, 1986, 1991, 1996) and mortality data since 1991
 - **Switzerland National Cohort** created in 2005 and links anonymized census records to death or emigration records since 1990 census (over 100 million person-years of follow up during which 1,122,239 deaths occurred)
 - Samples only:
 - **France “Permanent Demographic Sample”** links all censuses and vital events since 1968 (n= 2.7 million persons by end 2013 including 600,000 from birth)
 - **U.K. Longitudinal Study** (since 1971 for England and Wales, Scotland since 1991 and Northern Ireland since 2001), 1% sample of the population
 - **USA forward linkage:** National Longitudinal Mortality Study and the National Health Interview Survey. The NLMS consists of various rounds of the Current Population Survey (also including census data in some years) linked to subsequent deaths using the National Death Index (NDI) system. Similarly, individual data from the NHIS in various years have been linked to subsequent death records using the NDI.
 - **USA backward linkage:** Kitagawa and Hauser linked a sample of death records for a time period in the early 1960s back to 1960 census records, in their classic study of socioeconomic mortality differentials in the United States.

References about national cohorts based on record linkage of census and vital registration

- Bhopal, Raj et al. (2011). Cohort Profile:- Scottish Health and Ethnicity Linkage Study of 4.65 million people exploring ethnic variations in disease in Scotland. *International Journal of Epidemiology* 2010;1–8. doi:10.1093/ije/dyq118
- Bopp, Matthias et al. (2009). Cohort Profile - The Swiss National Cohort—a longitudinal study of 6.8 million people. *International Journal of Epidemiology* 2009; 38:379–384. doi:10.1093/ije/dyn042
- Boyle, Paul et al. (2009). Cohort Profile: The Scottish Longitudinal Study (SLS). *International Journal of Epidemiology*; 38:385–392. doi:10.1093/ije/dyn087
- Couet, Christine (2007). INSEE's Permanent Demographic Sample (EDP). INSEE. *Courrier des statistiques*, English series no. 13, 2007. pp. 29-38.
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- O'Reilly, Dermot et al. (2012). Cohort description: The Northern Ireland Longitudinal Study (NILS). *International Journal of Epidemiology*; 41:634–641. doi:10.1093/ije/dyq271

THANK YOU !