Mortality of people with intellectual disabilities

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Abstract

This symposium will focus on mortality of people with intellectual disabilities. Evidence suggests that considerable inequities exist in relation to the deaths of people with intellectual disabilities when compared to the general population. The papers in this collection focus address the extent of these inequities, some of the challenges in fully understanding them, and what England is doing to try and translate this knowledge into improved service provision.

Lisa O’Leary and colleagues from the University of Glasgow, Scotland set the scene by reporting on the findings of two systematic reviews: one focused on mortality and intellectual disabilities and the second focused on mortality and Down syndrome. Comparisons between studies has been hampered by different approaches to the methodology employed across existing analyses, but the general picture is one of considerable inequality in relation to age at death of people with intellectual disabilities.

Professor Mary McCarron and colleagues from Trinity College Dublin, Ireland describe the findings of their study drawing on data from the Census in Ireland and the National Intellectual Disability Database between 2003 and 2012. They report little change in the average age at death over the 10 year period examined, and recommend that an established set of measures of mortality should be used for ease of comparison across studies.

Fred Dunwoodie-Stirton provides additional insights by examining inconsistency in reporting that a person had intellectual disabilities on their cause of death certificate, and the effect this might have on our understanding of the cause of death. Inconsistent or inaccurate reporting of cause of death can lead to erroneous national data about the cause of death of people with intellectual disabilities and hinder our efforts to reduce health inequities in this population.

Professor Pauline Heslop describes how one country (England) is attempting to translate knowledge about premature mortality of people with intellectual disabilities into service improvement initiatives. She describes the national Mortality Review programme which is supporting local areas to review the deaths of people with intellectual disabilities aged between 4-74 years, and to make improvements in care delivery based on review findings.

Together, the papers present a clear message: that although our knowledge of mortality of people with intellectual disabilities is improving, there is still much to be done to ensure comparability across studies, and that the findings of such research must then used to reduce inequalities in mortality in this population.

Life expectancy and causes of death of people with Intellectual disabilities and people with Down syndrome: Findings from two systematic reviews

Lisa O’Leary, Laura Hughes-Mccormack, Kirsty Dunn, Sally- Ann Cooper.

Background: People with intellectual disabilities are thought to have lower life expectancy than the general population. The Down syndrome physical phenotype includes congenital heart defects, depressed immune function, altered craniofacial dimensions and ciliary dyskinesis, so cause of death profile may differ. Concern has been expressed about avoidable and preventable deaths in people
with intellectual disabilities, hence the importance of synthesising the evidence on life expectancy and causes of death.

**Method:** Two systematic reviews were undertaken on (1) mortality and intellectual disabilities (2) mortality and Down syndrome. Electronic databases were searched for key words relating to intellectual disabilities AND death. Titles, abstracts and full papers were assessed using strict inclusion/exclusion criteria. Study information was extracted, tabulated, and quality reviewed. Prospero registration number: CRD42015020161.

**Results:** 26 intellectual disabilities studies and 35 Down syndrome studies met the inclusion criteria. They used differing populations, and methods, which made meta-analysis inappropriate. However common trends were that life expectancy of individuals with intellectual disabilities was about 20 years lower than the general population, with a standardised mortality ratio (SMR) in the range of 2-5. SMR was higher in females than males, and in people with pre-existing comorbidities, more severe intellectual disabilities, and Down syndrome. Respiratory disease was one of the leading causes of death in the intellectual disabilities and Down syndrome populations, but there are limitations in these analyses of death certification data. 40% of deaths may be amenable to care.

**Conclusions:** In view of their shorter life expectancy, and different causes of death than the general population, interventions need to be tailored for the death profile of people with intellectual disabilities and people with Down syndrome.

**Mortality Rates in the General Irish Population Compared to those with an Intellectual Disability from 2003 to 2012**

Mary McCarron, Rachael Carroll, Caraiosa Kelly, and Philip McCallion

**Background:** Higher mortality rates and younger age at death among people with intellectual disability has been historically found compared to the general population. Differing approaches in the methodology employed across analyses has been a barrier to comparing studies on mortality.

**Method:** The Census in Ireland and the National Intellectual Disability Database (NIDD) provide the source of the data from 2003 to 2012. To compare mortality rates a standardized mortality ratio (SMR) was calculated along with the average age at death. The influence of age, gender and level of intellectual disability was examined.

**Results:** On average, people with an Intellectual disability were dying 19 years earlier than the general population. Standardized mortality rates were four times higher in people with an intellectual disability. Similar to the general population, women with intellectual disability were living longer than males with intellectual disability. However, differences in survival as compared to the general population were greater for these women. Death occurred earlier the more severe the level of intellectual disability and little change has been observed in the average age at death over the 10 year period examined.

**Conclusions:** An established set of measures of mortality should be used for ease of comparison across studies, such as standardized mortality ratios in addition to average age at death is recommended. Greater standardization in use of data sets including the whole population is recommended, given high levels of earlier deaths in people with intellectual disability.
Title: Inconsistent recording of intellectual disabilities on Cause of Death Certificates

Fred Dunwoodie-Stirton

**Background:** In order to reduce the premature deaths of people with intellectual disabilities it is essential that research on the topic can be conducted using accurate and reliable death certificating data. There has been much concern internationally that the current system is affected by inconsistencies in reporting intellectual disabilities on cause of death certificates. This is a substantial obstacle for mortality reviews (and similar studies), thus hindering the study of trends and linkages amongst groups and morbidities.

**Method:** To highlight key issues and their impacts, a review of associated literature was conducted. To explore and expand upon identified themes, data from the Confidential Inquiry into Premature Deaths of People with Intellectual Disabilities were retrospective analysed.

**Results:** The principle findings were inconsistency in the recording of intellectual disabilities on cause of death certificates and the apparently erroneous inclusion of intellectual disabilities as an underlying cause of death. The research highlighted a number of possible reasons for this: multiple coding options for intellectual disabilities; inconstancies in interpreting contributing causes of death; and the (lack of) knowledge that the deceased person had intellectual disabilities.

**Conclusions:** The current system for recording intellectual disabilities on cause of death certificates is inadequate. It hinders research that may support reducing inequalities faced by people with intellectual disabilities as well as giving misleading information to those who knew the deceased. In order to improve the system a number of proposals are made, including: greater clarity and guidance from the World Health Organisation in ICD11; an additional section on cause of death certificates to include conditions present at death, which are not associated with the death; and improved training and guidance for medical practitioners who write death certificates.

**Learning lessons from deaths of people with intellectual disabilities to improve services in England: the Mortality Review Programme in England**

Pauline Heslop, Programme Lead, LeDeR programme, University of Bristol

**Background:** Since the 1990s there have been a number of reports and case studies that have consistently highlighted that in England people with intellectual disabilities die younger than people without intellectual disabilities. Recent analysis of data from the Primary Care Research Database suggested that the all-cause standardised mortality ratio for people with intellectual disabilities was 3.18, and that people with intellectual disabilities had a life expectancy 19.7 years lower than people without intellectual disabilities.

The LeDeR Programme has been set up to contribute to improvements in the quality of health and social care for people with intellectual disabilities in England by supporting local areas to review deaths of people with intellectual disabilities.

**Method:** Initial reviews are undertaken of all deaths notified to the LeDeR programme of people with intellectual disabilities aged 74. Where indicated, a full multiagency review is conducted.

From 2016-2017, and possibly longer, deaths of young people aged 18-24, and of people from Black and Minority Ethnic communities are subject to priority themed review; each of these receive a full multiagency review.
Results: Considerable ‘set up’ activities have taken place in relation to agreeing a process for mortality reviews, developing a secure web-based platform to support the work, establishing governance arrangements for the work, training local reviewers and piloting the work in different regions of England. The inclusion of people with intellectual disabilities and their families has been crucial to the programme’s work.

Conclusions: To our knowledge, this is the first national programme of mortality reviews of people with intellectual disabilities in the world. It is a complicated and challenging programme that is primarily a service improvement initiative that is about learning lessons and making changes to improve the lives of, and support for people with intellectual disabilities.