



## RESEARCH BRIEF #42

March 4, 2021

### More Uncertainty Leads to Less Accuracy on Death Certificates for Adults with Intellectual Disability

Erin Bisesti and Scott D. Landes

Despite the fact that intellectual disability does not meet the U.S. Center for Disease Control and Prevention's (CDC) criteria as an underlying cause of death,<sup>1</sup> between 2012 and 2016 in the U.S., 25.9% of death certificates for adults with an intellectual disability inaccurately identified their disability as the underlying cause of death.<sup>2</sup> This inaccuracy in reporting makes preventing premature deaths in this population more difficult because it [obscures higher rates of other potentially preventable causes of death](#), such as choking-related deaths.<sup>2</sup>

In general, more uncertainty about the death leads to more errors on the death certificate. Uncertainty arises when the person certifying the death certificate has unanswered questions about the actual causal sequence leading to death.<sup>3</sup> The level of uncertainty surrounding a death often relates to how much medical information is available about a decedent at the time of death. This can vary by place of death (e.g., in a non-medical setting versus a hospital), the number of diseases documented at the time of death, and how much interaction the decedent had with medical providers throughout their life.

Uncertainty surrounding a death may be even higher for decedents with intellectual disability because medical providers often have limited knowledge of disability<sup>4</sup> and may be unsure about where to report it on the death certificate.<sup>5</sup> Thus, it is imperative to understand the specific factors present at the time of death that may increase uncertainty and the chance that medical providers will inaccurately report intellectual disability as the underlying cause of death.

This brief summarizes the findings from our recently published peer-reviewed [study](#)<sup>6</sup> that examined whether uncertainty surrounding deaths among adults with intellectual disability is associated with the inaccurate reporting of intellectual disability as the underlying cause of death on death certificates. It used death certificate data for adults with intellectual disability between 2005 and 2017.

#### KEY FINDINGS

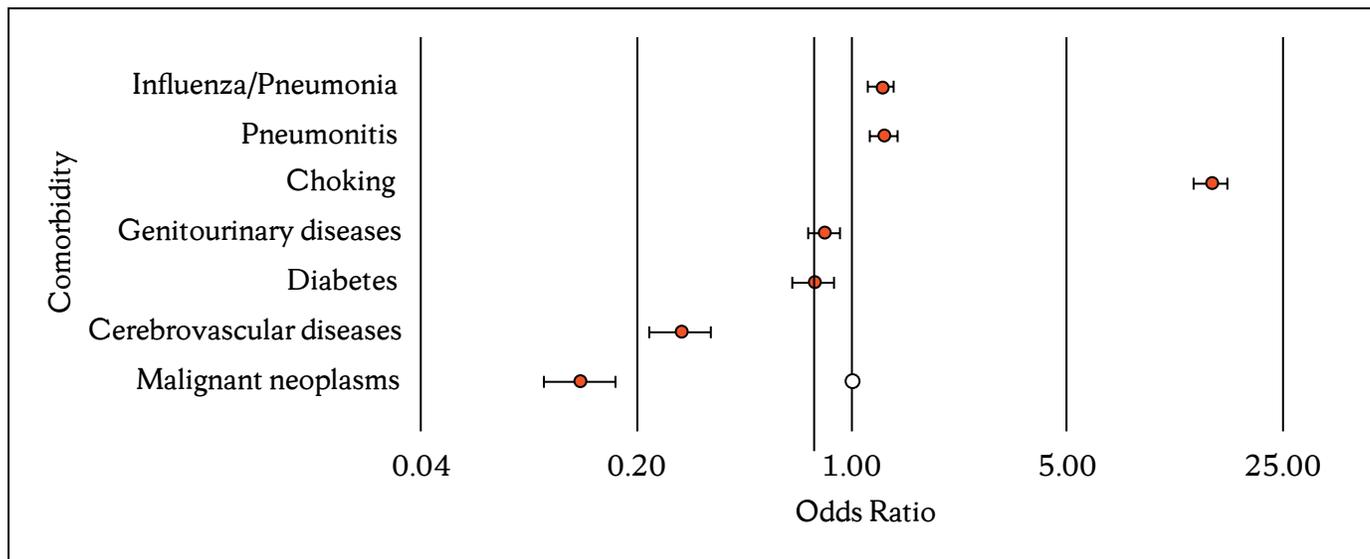
- Causes of death are often inaccurately reported on death certificates for individuals with intellectual disability.
- Inaccurate reporting occurs most often when death certifiers are uncertain about the cause of death.
- For example, inaccurate reporting of intellectual disability as the underlying cause of death was 14.7 times more likely if choking was also listed on the death certificate.
- More certain causes of death, such as cancer and Alzheimer's/dementia, resulted in more accurate cause of death reporting.
- Younger males, Hispanics, adults with 0-8 years of schooling, and those who had their disability listed as severe/profound were most likely to have their cause of death inaccurately reported.

## Inaccurate Reporting is Not Universal

Overall, 21.1% of decedents with intellectual disability had their disability inaccurately reported as the underlying cause of death. However, not all demographic groups were equally likely to have their underlying causes of death inaccurately reported. Intellectual disability was most commonly reported as the underlying cause of death for those who had their disability listed as severe/profound, died at younger ages, were male, were Hispanic, and had lower levels of education. These factors indicate a potentially lower frequency or quality of lifetime physician-patient interaction prior to death.

## More Uncertainty Leads to Less Accuracy

Intellectual disability was more likely to be inaccurately reported in instances when choking or a respiratory disease, such as pneumonitis or influenza/pneumonia, was reported on the death certificate (see Figure 1). Most notably, the odds of having the underlying cause of death inaccurately reported was 14.7 times higher if choking, an external cause of death often surrounded by a high level of uncertainty,<sup>7</sup> was listed on the death certificate. In comparison, when a clearly specified internal cause of death, such as malignant neoplasms (cancer) or Alzheimer’s disease or dementia, was listed on the death certificate, the odds of inaccurate reporting were much lower. In fact, those with intellectual disability who had a cancer diagnosis on their death certificate had 83% lower odds than those who did not to have their disability inaccurately reported as their underlying cause of death.



**Figure 1. The Odds of Having Intellectual Disability Reported as the Underlying Cause of Death are Highest for Those Who Die from Choking**

Data Source: 2005-2017 US Multiple Cause-of-Death Mortality Files (N=26,436). Odds ratios are from “[Uncertainty and the reporting of intellectual disability on death certificates: a cross-sectional study of US mortality data from 2005 to 2007](#)”, *BMJ Open* 2021;11:e045360

Notes: The x-axis is represented in a logarithmic scale. Error bars represent 95% confidence intervals. Estimates to the right of the solid black line indicate significantly greater odds of having intellectual disability inaccurately reported on the death certificate for decedents who had the comorbidity listed on the death certificate compared to people who did not. Estimates to the left of the solid black indicate significantly lower odds of having intellectual disability inaccurately reported on the death certificate for decedents who had the comorbidity listed on the death certificate compared to people who did not.

## Recommendations for Reporting

Our findings suggest that increased uncertainty surrounding deaths increases the chance that intellectual disability is inaccurately reported as the underlying cause of death. Because efforts to reduce premature mortality among adults with intellectual disability are highly dependent on death certificate data, it is imperative that those certifying the death

certificate, even in instances of increased uncertainty, accurately identify the *actual* disease or injury that caused the death. If a valid underlying cause of death cannot be identified, it is not acceptable and is in fact detrimental, to report intellectual disability as the underlying cause of death. Instead, the CDC states that in instances when the underlying cause of death can not be identified, it can be reported as ‘unspecified natural causes’.<sup>8</sup> In addition, a critical final step for the death certifier is to report the intellectual disability in Part II of the death certificate as a condition that was present at the time of death.<sup>5</sup> This will ensure the ability to monitor mortality trends for people with intellectual disability.

## Data and Methods

This study used U.S. National Vital Statistics System restricted-use 2005-2017 Multiple Cause of Death files. It included the death certificates of adults, ages 18 and over, who had an ICD-10 code for intellectual disability (F70-79) reported as the underlying or a multiple cause of death, and who died in their state of residence between January 1, 2005 and December 31, 2017 (N=26,555). Full methodological details can be found in the published paper.

## References

1. National Center for Health Statistics. 2003. Physicians' handbook on medical certification of death. Centers for Disease Control and Prevention. [https://www.cdc.gov/nchs/data/misc/hb\\_cod.pdf](https://www.cdc.gov/nchs/data/misc/hb_cod.pdf).
2. Landes SD, Stevens JD, Turk MA. “Obscuring effect of coding developmental disability as the underlying cause of death on mortality trends for adults with developmental disability: a cross-sectional study using US Mortality Data from 2012 to 2016.” *BMJ Open*. 2019;9:e026614:1-10.
3. Wall MM, Huang J, Oswald J, et al. 2005. Factors associated with reporting multiple causes of death. *BMC Med Res Methodol* 5:4.
4. Iezzoni, Lisa I., Sowmya R. Rao, Julie Ressler, Dragana Bolcic-Jankovic, Nicole D. Agaronnik, Karen Donelan, Tara Lagu and Eric G. Campbell. 2021. "Physicians' Perceptions of People with Disability and Their Health Care." *Health Affairs* 40(2):297-306. doi: 10.1377/hlthaff.2020.01452.
5. Landes, Scott D., Margaret A. Turk and Emily Lauer. 2020. "Recommendations for Accurately Reporting Intellectual and Developmental Disabilities on Death Certificates." *American Journal of Preventive Medicine* 59(6):892-95. doi: 10.1016/j.amepre.2020.05.028.
6. Landes SD, Turk M, and Bisesti E. 2021. “Uncertainty and the Reporting of Intellectual Disability on Death Certificates: A Cross-Sectional Study of US Mortality Data from 2005-2017.” *BMJ Open* 2021;11:e045360:1-10.
7. Hanley, Megan Joy. 2018. "Exploring the Social Context of Choking and Its Implications for Care." University of Tasmania.
8. Center for Disease Control and Prevention. 2015. Possible solutions to common problems in death certification. Centers for Disease Control and Prevent, National Center for Health Statistics. [https://www.cdc.gov/nchs/nvss/writing-cod-statements/death\\_certification\\_problems.htm](https://www.cdc.gov/nchs/nvss/writing-cod-statements/death_certification_problems.htm).

## Acknowledgments

Research reported in this publication was supported by the National Institute on Aging (NIA; grant R03AG065638). The authors are affiliates of the Center for Aging and Policy Studies, which receives funding from the National Institute on Aging (grant # P30AG066583). The authors would like to thank Shannon Monnat for edits on an earlier version of this brief.

## About the Authors

**Erin Bisesti** (embisest@syr.edu) is a PhD student in the Department of Sociology and an Affiliate in the Policy, Place, and Population Health Lab and Center for Aging and Policy Studies in the Maxwell School of Citizenship and Public Affairs at Syracuse University (SU). **Scott D. Landes** (sdlandes@maxwell.syr.edu) is an Associate Professor of Sociology, Faculty Associate of the Aging Studies Institute, and a Research Affiliate of the Lerner Center for Public Health Promotion and Center for Aging and Policy Studies in the Maxwell School at SU.

Lerner Center for Public Health and Promotion  
426 Eggers Hall  
Syracuse, New York 13244  
syracuse.edu | lernercenter.syr.edu

Center for Aging and Policy Studies  
314 Lyman Hall  
Syracuse, New York 13244  
syracuse.edu | asi.syr.edu/caps