

Center for Public Representation

#### Life Expectancy Estimates: A Survey of Research on the Reliability of Prognosis

The medical studies and journal articles collected and summarized below explore the accuracy and reliability of life expectancy predictions, including individual prognosis with treatment. They include studies of patients with advanced terminal illness, life expectancy predictions under "10 year" rule, prognosis in emergency triage situations, and the potential for discrimination and unconscious bias when predicting life expectancy based on age, race or disability. This survey was prepared as a resource for advocates responding to the use of prognosis as a criteria for the allocation of scare medical resources under Crisis Standards of Care.<sup>1</sup> Additional resources on health care rationing can be found at <u>https://www.centerforpublicrep.org/covid-19-medical-rationing/</u>.

### Michael G. Clarke, et al., *How accurate are doctors, nurses, and medical students at predicting life expectancy?*, 20 European J. of Internal Medicine 640 (2009), <u>https://www.sciencedirect.com/science/article/pii/S0953620509001253?casa\_token=aYBJ915</u> <u>f5eoAAAAA:pli2VZRD2aBrVIZloWQ8lRG4A\_R\_M4NBTHi\_fXFrgwKUY8\_jj12IhHsVZ</u> <u>Q23DEvuCqpNwFzl5A</u>.

- Population: vignettes of hypothetical patients with non-terminal medical conditions.
  - Medical Conditions: cardiovascular, respiratory, endocrine, neurological, and others (epilepsy, depression, myeloma, obesity, renal failure).
  - The patients in the scenarios had a mean age of 68 (range 55 to 82) years and actuarial LE of 11.6 years (range 2 to 28 years).
- "The aim of this study was therefore to investigate the consistency, accuracy and precision with which doctors, nurses and medical students predicted LE in a hypothetical group of patients based on age, sex and comorbidity through comparison with population-based statistical predictions derived by actuarial techniques."
  - Predictions were compared with life expectancy derived from actuarial tables, incorporating a series of numerical mortality ratios used by the life insurance industry.
- "Studies examining the accuracy of 10-year LE prediction, predominantly within the context of prostate cancer, have demonstrated a tendency amongst doctors to underestimate LE, with an accuracy of 66–82%." (Citing Wilson, Krahn, Walz.)
- "[Life expectancy] was underestimated on 64% of occasions and overestimated 27% of the time, with just 9% being correct."
  - Compare to terminal cases, where physicians tend to *overestimate* life expectancy.
- "Compared to actuarial estimates, doctors, nurses and medical students were inaccurate and imprecise in their assessment of patient LE tending to either over- or underestimate LE with a [root mean squared error] of around 5 years. Fewer than 10% of predictions

<sup>&</sup>lt;sup>1</sup> Thank you to Lauren Vandemortel, law student at Boston University, for researching and authoring this document.

exactly matched actuarial LE and less than half predicted LE to within 25% of actuarial LE. This would imply that most health care professionals would either under or overestimate LE by more than 1 year for a patient expected to live 4 years and by more than 3 years for a patient expected to live 12 years."

#### PROGNOSIS FOR THOSE WITH ADVANCED TERMINAL ILLNESS

# Nicola White, et al., *A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts?*, PLOS One (2016), <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4999179/pdf/pone.0161407.pdf</u>.

- Review of 42 studies.
- "[T]he evidence suggests that clinicians' predictions are frequently inaccurate."
- *Horizon Effect*: clinicians should be more accurate at recognizing a shorter rather than a longer prognosis.
  - Recent UK study reviewing care pathways for dying patients showed that "clinicians are not very accurate at recognizing which patients are imminently dying."
- Accuracy of categorical prognostic estimates ranged from 23% to 78%. Did not calculate an overall accuracy score.

## Monica Krishnan, et al., *Predicting life expectancy in patients with advanced incurable cancer: a review*, 11 J. of Supportive Oncology 68 (2013),

https://pdfs.semanticscholar.org/fff5/c81fac058af5aa98b4e6283ad06f1c2ca872.pdf.

- Population: patients with advanced, incurable solid tumors.
  - Oncologists deciding whether or not to refer them to hospice care (which requires a physician-predicted prognosis of six months or less).
- Prognosis estimates based on physicians' clinical experience and comprehensive knowledge of the patient. Among advanced cancer patients, multiple studies have found this method to be "largely unreliable, with accuracy ranging from 20%-60%." Physicians tend to overestimate life expectancy among advanced cancer patients by a median of 1.1 months (Vigano et al.).

## Antonio Vigano, et al., *The relative accuracy of the clinical estimation of the duration of life for patients with end of life cancer*, 86 Am. Cancer Society J. (2000),

https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/(SICI)1097-0142(19990701)86:1%3C170::AID\_CNCP23%3F3.0\_CO:2\_S

- 0142(19990701)86:1%3C170::AID-CNCR23%3E3.0.CO;2-S.
  - Population: patients with terminal cancer (lung, breast, gastrointestinal system, prostate).
    Prognosis estimated within 30 days of entering the terminal phase.
  - Physicians overestimated survival by a median of 1.1 months.
  - Oncologists accurately predicted survival (within 1 month) of 25%, underestimated survival for 23%, and overestimated survival for 52%.
    - For those who actually survived less than 2 months, 31% of physicians accurately estimated prognosis.
    - For those who actually survived 2-6 months, 68% of physicians accurately estimated prognosis.

- For those who actually survived more than 6 months, 54% of physicians accurately estimated prognosis.
- Note: this article was cited in many other subsequent articles.

# Stephanie Cheon, et al., *The accuracy of clinicians' predictions of survival in advanced cancer: a review*, 5 Annals of Palliative Medicine 22 (2016), http://apm.amouraups.com/article/view/7744/8503

http://apm.amegroups.com/article/view/7744/8503.

- Review of 15 studies of clinicians' predictions of survival in advanced cancer (characterized by accelerated decline in health over the final weeks of a patient's life) patients.
- In 9 studies, health care professions overestimated survival.

# Pedro E. Perez, et al., *Longitudinal Temporal and Probabilistic Prediction of Survival in a Cohort of Patients With Advanced Cancer*, 48 J. of Pain & Symptom Management 875 (2014), <u>https://www.sciencedirect.com/science/article/pii/S0885392414001894</u>.

- Population: patients with advanced cancer in their last few weeks of life.
- Clinician Predictions of Survival:
  - Temporal CPS: providing an estimated duration of survival.
    - From other studies, reported accuracies between 20% and 30%.
  - Probabilistic CPS: providing the probability that a patient would survive for a predefined length of time (e.g., 20% chance of being alive at one month).
- Physicians gave daily estimates of temporal and probabilistic CPS in last 14 days of patients' lives (median survival was 8 days).
- "Physicians' accuracy with temporal CPS was relatively stable over time with accuracies between 10% and 35%," *i.e.* accuracy did not increase as patient drew closer to death.
- "The accuracy of the probabilistic CPS was consistently higher than the accuracy of temporal CPS. Interestingly, the accuracy of temporal CPS remained poor over time, and probabilistic CPS decreased inaccuracy as death approached."
- "Probabilistic CPS was consistently more accurate than temporal CPS over the last 14 days of life; however, its accuracy decreased as patients approached death."

# Belinda E. Kiely, et al., *The Median Informs the Message: Accuracy of Individualized Scenarios for Survival Time Based on Oncologists' Estimates*, 31 J. of Clinical Oncology 3565 (2013),

https://www.researchgate.net/profile/David\_Wyld/publication/256425450 The Median Inf orms the Message Accuracy of Individualized Scenarios for Survival Time Based on Oncologists'\_Estimates/links/55e3b11d08aecb1a7cc9d724/The-Median-Informs-the-Message-Accuracy-of-Individualized-Scenarios-for-Survival-Time-Based-on-Oncologists-Estimates.pdf.

- Study: 21 oncologists estimated the "median survival of a group of identical patients" for each of 114 patients with advanced cancer.
- "In a previous study, we asked oncologists to estimate the survival time of 102 newly referred patients with incurable cancer by estimating the median survival of a group of similar patients. We found that approximately 10% of patients died within one sixth of their estimated survival time (worst-case scenario), approximately 50% lived between

half to double their estimated survival time (typical scenario), and approximately 10% lived for three or more times their estimated survival time (best-case scenario)."

- Oncologists' estimates were relatively well-calibrated, with 61% of patients living longer and 39% living shorter than their estimated survival time.
  - Median survival time was 11 months.
  - Median estimated survival time was 9 months.

## Paul Glare, et al., A systematic review of physicians' survival predictions in terminally ill cancer patients, 327 BMJ (2003),

https://www.bmj.com/content/bmj/327/7408/195.full.pdf?casa\_token=H6AGdIxahOwAAA AA:9JVhyj4NxlJINyWXGpVb86S70P3eMip5\_NN1IR\_SJ5JBtgwDaPG3L8SDvvqciMF\_qf g7TmfdCWU.

- Population: 12 studies of 1594 patients with terminal cancer (people with median survival or 4 weeks).
- Clinical predictions of survival were accurate to within a week in only 25% of cases. They were correct to within 2 weeks in 43% of cases and to within 4 weeks in 27% of cases.
- Physicians consistently overestimated survival: the median clinical prediction of survival was 42 days and the median actual survival was 29 days, a difference of 13 days.

# Marco Maltoni, et al., *Prognostic Factors in Advanced Cancer Patients: Evidence-Based Clinical Recommendations—A Study by the Steering Committee of the European Association for Palliative Care*, 23 J. of Clinical Oncology 6240 (2005),

https://ascopubs.org/doi/full/10.1200/JCO.2005.06.866?url\_ver=Z39.88-2003&rfr\_id=ori:rid:crossref.org&rfr\_dat=cr\_pub%20%200pubmed.

- Study: looked at 16 papers (with total of 468 hospice outpatients) assessing the accuracy of clinical prediction of survival.
  - Median survival in populations of advanced cancer patients undergoing palliative care is less than 90 days.
- Correlation between actual survival and COS of 0.2 to 0.65, with doctors twice as likely to be overoptimistic.
- "Prognostic accuracy in this population seems to be the exception rather than the rule."
  - Only 20% of prognoses were accurate.
  - Doctors overestimated survival by a factor of approximately 5.
  - CPS is more than twice as likely to be overoptimistic versus overpessimistic and to overestimate the length of actual survival by a factor of between 3 and 5
- CPS subject to the "Horizon Effect" (the greater accuracy of short-term predictions over long-term predictions).

# Nicholas A. Christakis, et al., *Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study*, 320 BMJ 469 (2000), https://www.bmj.com/content/320/7233/469.long.

- Population: terminally ill patients (cancer, AIDS, and other conditions) in hospices with median survival of 24 days.
- Only 20% of predictions were accurate (within 33% of actual survival); 63% were overoptimistic and 17% were overpessimistic.

- Overall, doctors overestimated survival by a factor of 5.3.
- The better the doctor knew the patient, the more likely the doctor was to err.
- "Doctors are inaccurate in their prognoses for terminally ill patients and the error is systematically optimistic. The inaccuracy is, in general, not restricted to certain kinds of doctors or patients."

## Elizabeth B. Lamont, et al., *Prognostic Disclosure to Patients with Cancer near the End of Life*, 134 Annals of Internal Medicine 1096 (2001),

<u>https://www.researchgate.net/publication/11928110\_Prognostic\_Disclosure\_to\_Patients\_wit</u> <u>h\_Cancer\_near\_the\_End\_of\_Life</u>.

- Of the discrepant survival estimates, most (70.2%) were optimistically discrepant.
- Median formulated prognosis was 75 days (CPS) and median communicated prognosis was 90 days (what doctors actually told their patients). Physicians would have overstated their formulated prognoses to patients by a factor of 1.2 days.
  - Median actual survival was 26 days.

## M. Molly McMahon, et al., *Medical and Ethical Aspects of Long-term Enteral Tube Feeding*, 80 Mayo Clinic Proceedings 1461 (2005),

https://www.mayoclinicproceedings.org/article/S0025-6196%2811%2961440-7/pdf.

- Findings covered: Jane E. Brody, *Tough Questions to Answer, To Answer to Hear*, N.Y. Times (Mar. 6, 2007), <u>https://www.nytimes.com/2007/03/06/health/06mbrody.html</u>.
- "Accurately predicting life expectancy in terminally ill patients is challenging and imperfect. Physicians provide survival estimates by clinical experience and intuition and are typically optimistic in their estimates of patient survival. A study of 343 physicians found that for 468 terminally ill patients admitted to outpatient hospice programs, only 20% of survival predictions accurately predicted the actual day of death; 63% of predictions were overly optimistic. [citing Christakis 2000 and Glare 2003.] Another study reported that when physicians estimated prognoses for patients who were terminally ill with cancer and were referred for hospice care, median observed survival was 24 days, formulated (eg, clinical experience and intuition) survival was 75 days, and survival communicated to patients was 90 days. [citing Lamont 2001]" 1469-70.

# Irene J. Higginson, et al., Accuracy of prognosis estimates by four palliative care teams: a prospective cohort study, 1 BMC Palliative Care (2002), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC88964/.

#### PROGNOSIS RE: 10-YEAR RULE

Jochen Walz, et al., *Clinicians are poor raters of life-expectancy before radical prostatectomy or definitive radiotherapy for localized prostate cancer*, 100 BJU Int'l 1254 (2007), https://bjui-journals.onlinelibrary.wiley.com/doi/epdf/10.1111/j.1464-410X.2007.07130.x.

• Population: case-vignettes of 50 patients treated with either radical prostatectomy or external beam radiotherapy for prostate cancer, and who either survived for >10 years or died earlier with no evidence of disease relapse.

- 10-year rule is the most frequently cited life-expectancy benchmark for delivering definitive therapy to patients with localized prostate cancer.
- Urology clinicians asked to predict the survival at 10 years (yes/no).
  - $\circ$  Of the 50 cases, 20 did not survive for >10 years.
  - Clinicians estimated a mean of 23 deaths before 10 years (pessimistic). Mean overall predictive accuracy of life expectancy predictions was 0.68.
- "Clinicians are relatively poor at predicting [life expectancy]."
- "Our study showed that clinicians' ability to predict the 10-year [life expectancy] was moderate at best. The mean [area under the curve (AUC)] of all 19 participants was only 0.68, where an AUC of 0.5 would imply a prediction no better than equal chance, and an AUC of 1.0 would imply a perfect prediction."

# James R.M. Wilson, et al., *The assessment of patient life-expectancy: how accurate are urologists and oncologists?*, 95 BJU Int'l 794 (2005), <u>https://bjui-</u>

journals.onlinelibrary.wiley.com/doi/epdf/10.1111/j.1464-410X.2005.05403.x.

- Population: 70 patient case scenarios containing detailed medical histories
  - $\circ$   $\,$  Doctors asked to predict the patient's 10-year life expectancy.
- Compared with actuarial estimates, doctors underestimated the 10-year survival probability by an overall mean of 10.8%.
  - Range: mean underestimation of 33.2% to a mean overestimation of 3.9%.
  - Variation around these means was considerable for each doctor, the standard deviations being 14.5-20.9%.
- "Doctors were poor at predicting 10-year survival, tending to underestimate when compared with actuarial estimates. There was also substantial variability both within and between doctors. The inaccuracy, imprecision and inconsistency amongst the doctors in assessing patient life-expectancy is an important finding and has significant implications for managing patients."

# Murray D. Krahn, et al., The ten-year rule revisited: accuracy of clinicians' estimates of life expectancy in patients with localized prostate cancer, 60 Urology 258 (2002),

https://www.sciencedirect.com/science/article/pii/S0090429502017120?casa\_token=LgqVh6 5sULYAAAAA:vCPlUlOsRy73mp\_s7BFtExFgVywl9wmkCQl0jT9R241OosXBb7pBht34H JM-41NvqEO2j9YXug.

- "10-year rule": curative therapy (surgery or radiation) should be offered to patients with life expectancy of at least 10 years.
- Clinicians' life expectancy estimates fell as patient age and comorbidity increased.
- 31% of the clinicians' estimates were within +/-1 year of the mean of the model's value for that scenario, 48% of their estimates were within 2 years of the mean of the model's values, and 67% of their estimates were within 3 years of the mean of the model's values.
- The average error for any clinician's estimate ranged from 2.4 to 5.2 years in the various scenarios.
- Clinicians were surprisingly accurate in estimating patients' life expectancy around the10-year benchmark. Overall, 82% of the clinicians' estimates correctly classified patients as having a life expectancy less than or greater than 10 years.
- Age, comorbidity, and estimated life expectancy, but not tumor stage, were significant independent predictors of treatment decision.

• "Our results indicate that clinicians, using un-aided clinical judgment, can use age and comorbidity information to predict patients' life expectancy with a modest degree of overall accuracy, but a high degree of operational accuracy with respect to the effective use of the 10-year rule."

Catherine S. Hibberd & Gerald M.Y. Quan, Accuracy of Preoperative Scoring Systems for the Prognostication and Treatment of Patients with Spinal Metastases, 2017 Int'l Scholarly Research Notices (2017), http://downloads.hindawi.com/archive/2017/1320684.pdf.

Kevin M.Y.B. Leung, et al., *Challenging the 10-year rule: The accuracy of patient life expectancy predictions by physicians in relation to prostate cancer management*, 6 Canadian Urological Ass'n 367 (2012), <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3478337/</u>.

#### PROGNOSIS IN EMERGENCY / TRIAGE / ICU SETTINGS

Joao Gabriel Rosa Ramos, et al., *Prognostication in urgent intensive care unit referrals: a cohort study*, BMJ Supportive & Palliative Care (2018),

https://www.repositorio.bahiana.edu.br:8443/jspui/bitstream/bahiana/3094/1/ARTIGO%2 0-%20ROGERIO%20DA%20HORA%20PASSOS%20-%202018-3.pdf.

- Assessment of the accuracy of physicians' predictions of hospital mortality in acutely deteriorating patients referred for urgent ICU admission.
- One year and twenty days after ICU referral:
  - For patients *without* disabilities that physicians predicted would survive, 65.6% survivors and 34.4% deceased.
  - For patients *with* severe disabilities (defined as severe cognitive impairment) that physicians predicted would survive, 33.6% survivors and 66.4% deceased.
  - For patients that physicians predicted would not survive, 5.6% survivors and 94.4% deceased.
- Conclusion that physicians are overly optimistic in predicting hospital mortality, and more optimistic for patients with severe disabilities.

# Monica Escher, et al., *ICU physicians' and internists' survival predictions for patients evaluated for admission to the intensive care unit*, 8 Annals of Intensive Care 108 (2018), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6236006/.

- Study: whether physicians' survival predictions correlate with the admission decisions and with patients' observed survival.
- 201 patients assessed for intensive care. 69.7% (140) were admitted to the ICU, and 28.6% of those admitted to the ICU died within 28 days. Of those not admitted to the ICU (61), 29.5% died within 28 days.
- "Our findings also show that both internists and ICU physicians are accurate about patient prognosis under different circumstances, i.e., at the time of triage and for continued care on the ward or for care in the ICU."

#### Jeremiah S. Hinson, et al., Accuracy of emergency department triage using the Emergency Severity Index and independent predictors of under-triage and over-triage in Brazil: a

### *retrospective cohort analysis*, 11 Int'l J. of Emergency Medicine (2018), <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5768578/</u>.

- *Emergency Department Triage*: performed to prioritize care for patients with critical and time-sensitive illness when demand for medical care outstrips capacity.
  - *Under-Triage*: failure to identify and differentiate patients with acutely severe illness (e.g., myocardial ischemia, sepsis) from those with less urgent needs (e.g., indigestion, minor infections), contributes to delays in time-sensitive interventions and to potentially avoidable clinical deterioration, morbidity, and mortality.
  - *Over-Triage*: inappropriate labeling of patients with non-urgent presentations to high acuity designations, may have indirect, but equally harmful effects.
- Initial ESI-determined triage score was classified as inaccurate for 16,426 of 96,071 (17%) patient encounters.
- One-fifth of all patients were classified as either under-or over-triaged upon emergency department arrival.
  - "[T]his was caused by both under-recognition of high acuity clinical presentations and overestimation of urgency in patients without severe illness
  - "[U]nder-triage was associated with increased hospital admission rates and greater likelihood for critical clinical outcomes. These findings are consistent with prior findings that failure to distinguish patients with critical and time-sensitive conditions contributes to the delays in disposition and time-sensitive treatments and to the increases in potentially avoidable morbidity and mortality."
  - "Advanced age was strongly associated with under-triage, suggesting the impact of patient age on initial presentation and clinical course is not well-recognized by ESI and under-appreciated by triage clinicians."
- "Despite rigorous and ongoing training of ESI users, a large number of patients in this cohort were under- or over-triaged. Advanced age, vital sign derangements, and specific chief complaints—all subject to limited guidance by the ESI algorithm—were particularly under-appreciated."

## Frank J. Voskens, et al., Accuracy of Prehospital Triage in Selecting Severely Injured Trauma Patients, 153 JAMA Surgery 322 (2018),

https://jamanetwork.com/journals/jamasurgery/fullarticle/2659625.

- Note: only read abstract.
- Analysis of the protocol itself, regardless of destination facility, resulted in an undertriage of 63.8% and overtriage of 7.4%.
- "More than 20% of the patients with severe injuries were not transported to a level I trauma center. These patients are at risk for preventable morbidity and mortality. This finding indicates the need for improvement of the prehospital triage protocol."

#### BIAS IN PROGNOSIS (AGE, DISABILITY, RACE)

Colin A. Zestcott, et al. *Examining the presence, consequences, and reduction of implicit bias in health care: A narrative review*, 19 Group Processes & Intergroup Relations 528 (2016), <a href="https://journals.sagepub.com/doi/pdf/10.1177/1368430216642029?casa\_token=ua6H4Mz\_R">https://journals.sagepub.com/doi/pdf/10.1177/1368430216642029?casa\_token=ua6H4Mz\_R</a>

#### pgAAAAA:UL1SR7kzPS\_CNddM1B\_hFVQZTppu\_zplRTvPlQpKmI1W9\_W4UJHB0FO 07asoE2tBLeaHia9pMvbr.

• "[S]ome studies suggest that implicit prejudice and stereotyping can impact the judgment and behavior of health care providers when they interact with stigmatized patients (e.g., Green et al., 2007; see Chapman, Kaatz, & Carnes, 2013, for a review)."

Michael J. Bullard, et al., *Guidance when Applying the Canadian Triage and Acuity Scale* (*CTAS*) to the Geriatric Patient: Executive Summary, 19 Canadian J. of Emergency Medicine S28 (2017), <u>https://www.cambridge.org/core/journals/canadian-journal-of-</u> <u>emergency-medicine/article/guidance-when-applying-the-canadian-triage-and-acuity-scale-</u> <u>ctas-to-the-geriatric-patient-executive-</u> <u>cummory/74C2CCC03C22EE8414PE0D7C70P87P43</u>

summary/74C2CCC93C22FF8414BF0D7C79B87B43.

- Realities amongst elderly patients that make it more difficult to accurately triage and prioritize include: atypical presentations of common diseases, cognitive impairment, effect of co-morbid conditions, polypharmacy (many healthy older people take more than 5 prescription medications), palliative and end-of-life care.
- Presence of cognitive impairment may make it more difficult to gather an accurate set of symptoms or for the person to understand or participate in the triage process.

#### Thomas Fassier, et al., *Who Am I to Decide Whether This Person Is to Die Today? Physicians' Life-or-Death Decisions for Elderly Critically III Patients at the Emergency Department-ICU Interface: A Qualitative Study*, 68 Annals of Emergency Medicine 28 (2016), <u>https://www.annemergmed.com/article/S0196-0644(15)01360-8/fulltext</u>.

- "When explaining how they decided whether to resuscitate elderly patients, participants revealed how both positive and negative stereotypes influenced their triage and end-of-life decisions. These decisions were dichotomous: whether or not to start resuscitation, to transfer to the ICU, and to admit to the ICU."
- "Decisions made in the ED appeared more challenging because of lack of time and no room dedicated to family conferences."
- "Two major complications were identified during triage and end-of-life decisions for elderly critically ill patients. In some situations, intensive care was delayed or denied because of an inappropriate triage or end-of-life decision, potentially increasing the risk of death. In other situations, disproportionate intensive care was imposed on dying patients because of a lack of an end-of-life decision, jeopardizing the quality of end-of-life care."
- "Physicians revealed that they did not rely on chronologic age to make triage and end-oflife decisions for elderly critically ill patients, but used the concept of physiologic age, which combined information about comorbidities, quality of life, and functional and mental status.... [I]t is worrying that life-or-death decisions are sometimes based on the unclear concept of physiologic age and perception of age status, which are less reliable than validated measures of function and quality of life."

# Mildred Z. Solomon, et al., *Covid-19 Crisis Triage—Optimizing Health Outcomes and Disability Rights*, New Eng. J. of Med. (2020), <u>https://www.nejm.org/doi/full/10.1056/NEJMp2008300</u>.

• "Scoring systems using quality-adjusted or disability-adjusted life-years should not be used. They are overtly discriminatory in explicitly counting a year for a person living with a disability as worth less than a year for an able-bodied person."

## Michelle M. Mello, et al., *Respecting Disability Rights—Toward Improved Crisis Standards of Care*, New Eng. J. of Med. 1 (2020),

#### https://www.nejm.org/doi/pdf/10.1056/NEJMp2011997?articleTools=true.

- "[HHS] guidance documents reflect awareness of biases in how the public evaluates the quality of life of persons with disabilities a problem that also affects physicians' judgments."
- "It is ethically preferable to avoid [basing triage decisions on long-term life expectancy] because long-term life expectancy is negatively affected by some disabilities and by social circumstances such as poverty and poor access to health care. Thus, using long-term life expectancy would probably unfairly disadvantage some persons with disabilities and exacerbate other health disparities. Moreover, predictions of long-term life expectancy are much more uncertain and prone to bias than predictions of short-term survival."

### Deborah Hellman & Kate Nicholson, *Rationing and Disability in a State of Crisis*, Va. Pub. L. & Legal Theory Research Paper No. 2020-33 (2020),

https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=3570088. (Note: can't download full paper, but covered in UVA article here: <u>https://www.law.virginia.edu/news/202004/hospitals-might-violate-law-rationing-schemes-professor-says</u>.)

• "[R]ationing approaches that have been reported across the country discriminate against people with disabilities because of either real or assumed reasons why someone with a disability might not recover as quickly or as well compared to others who are sick."

## National Council on Disability, *Medical Futility and Disability Bias*, Bioethics & Disability Series (2019), <u>https://perma.cc/MY63-33FZ</u>.

- "Several studies have demonstrated that health care providers' opinions about the quality of life of a person with a disability significantly differ from the actual experiences of those people. For example, one study found that only 17 percent of providers anticipated an average or better quality of life after a spinal cord injury (SCI) compared with 86 percent of the actual SCI comparison group. The same study found that only 18 percent of emergency care providers imagined that they would be glad to be alive after experiencing a spinal cord injury, in contrast to the 92 percent of actual SCI survivors."
- Medical professionals "often place too heavy a clinical focus on the disability, such that it 'overshadows' the acute reason for their visit."
- Moreover, "few physicians have the expertise and training necessary to accurately diagnose and treat people with disabilities; often, they simply do not know how to apply diagnostic standards to people who physically or mentally deviate from the statistical norm, or they fail to differentiate the conditions associated with the individual's disability from the acute symptoms behind their medical visit."
- Cited in Samuel R. Bagenstos, *Who Gets the Ventilator? Disability Discrimination in COVID-19 Medical-Rationing Protocols*, The Yale L. J. Forum (2020),

#### https://deepblue.lib.umich.edu/bitstream/handle/2027.42/155445/BagenstosEssay.pd f?sequence=1.

• "Moreover, reliance on expected number of years of survival as a justification for explicitly disability-based rationing raises many of the same concerns about democratic legitimacy, medical bias, and double jeopardy that reliance on quality-of-life measures does. Once again, we would be forcing disabled individuals to face deadly consequences because of societal decisions not to invest in sufficient treatments—decisions from which people with disabilities disproportionately lack access. Once again, we would be relying on medical judgments that are likely to be inflected by bias. And once again, we would be denying life-saving treatment at least in part because of societal discrimination—for discrimination against disabled individuals plays a key role in the poor health outcomes some of them experience."

# Catherine L. Auriemma, et al., *Eliminating Categorical Exclusion Criteria in Crisis Standards of Care Frameworks*, Am. J. of Bioethics 1 (2020), https://www.tandfonline.com/doi/pdf/10.1080/15265161.2020.1764141.

• "Even when purportedly "objective" criteria are employed to allocate health care resources, subjective notions of the quality or desirability of life with disabilities may play an influential role. These negative biases and assumptions often result in the devaluing of the lives of people with disabilities which contributes to health care inequities and discrimination in multiple sectors of society. Medical providers, especially those who adhere to the medical model of disability and who do not understand the lived experiences of people with disabilities, are not immune to biases against people with disabilities (Fitzgerald and Hurst 2017)."

## Chloe FitzGerald & Samia Hurst, Implicit bias in healthcare professionals: a systematic review, 18 BMC Med. Ethics 1 (2017),

#### https://bmcmedethics.biomedcentral.com/track/pdf/10.1186/s12910-017-0179-8.

- "Almost all studies found evidence for implicit biases among physicians and nurses. Based on the available evidence, physicians and nurses manifest implicit biases to a similar degree as the general population. The following characteristics are at issue: race/ethnicity, gender, socioeconomic status (SES), age, mental illness, weight, having AIDS, brain injured patients perceived to have contributed to their injury,3 intravenous drug users, disability, and social circumstances."
- "Twenty out of 25 assumption studies found that some kind of bias was evident either in the diagnosis, the treatment recommendations, the number of questions asked of the patient, the number of tests ordered, or other responses indicating bias against the characteristic of the patient under examination."
- "A variety of studies, conducted in various countries, using different methods, and testing different patient characteristics, found evidence of implicit biases among healthcare professionals and a negative correlation exists between level of implicit bias and indicators of quality of care."

## Lynne D. Richardson, et al., *Racial and Ethnic Disparities in the Clinical Practice of Emergency Medicine*, 10 Acad. Emergency Med. 1184 (2003),

https://onlinelibrary.wiley.com/doi/pdf/10.1197/S1069-6563(03)00487-1.

- "Situations, such as the emergency department (ED), that are characterized by time pressure, incomplete information, and high demands on attention and cognitive resources increase the likelihood that stereotypes and bias will affect diagnostic and treatment decisions."
- "[T]here is clear evidence that racial and ethnic disparities exist in the provision of emergency care."

Joel Achenbach, *Life Expectancy Improves for Blacks, and the Racial Gap is Closing, CDC Reports*, Wash. Post (May 2, 2017), <u>https://www.washingtonpost.com/news/to-your-health/wp/2017/05/02/cdc-life-expectancy-up-for-blacks-and-the-racial-gap-is-closing</u>.

• "Blacks in every age group under 65 continue to have significantly higher death rates than whites. Black life expectancy at birth is about 3<sup>1</sup>/<sub>2</sub> years lower than that of whites."

#### **Other Resources**

Sharona Hoffman, *Preparing for Disaster: Protecting the Most Vulnerable in Emergencies*, 42 UC Davis L. Rev. 1491 (2009), <u>https://lawreview.law.ucdavis.edu/issues/42/5/articles/42-5\_Hoffman.pdf</u>.

Wendy F. Hensel & Leslie E. Wolf, *Playing God: The Legality of Plans Denying Scarce Resources to People with Disabilities in Public Health Emergencies*, 63 Fla. L. Rev. 719 (2013), <u>https://scholarship.law.ufl.edu/cgi/viewcontent.cgi?article=1110&context=flr</u>. "Because life expectancy calculations lack scientific precision, moreover, this method leaves the door open to discriminatory animus in allocating care."

Mark S. Stein, *The distribution of life-saving medical resources: equality, life expectancy, and choice behind the veil*, 19 Soc. Phil. & Pol'y 212 (2002), <u>https://search.proquest.com/docview/205289351/fulltextPDF/33C92C90B07E4DFBPQ/1?accountid=9676</u>.

#### **News Articles**

Mike Baker, Whose Life is Worth Saving? In Washington State, People With Disabilities Are Afraid They Won't Make the Cut., N.Y. Times (Mar. 23, 2020), https://www.nytimes.com/2020/03/23/us/coronavirus-washington-triage-disabled-handicapped.html?action=click&module=RelatedLinks&pgtype=Article.

Mike Baker & Sheri Fink, At the Top of the Covid-19 Curve, How Do Hospitals Decide Who Gets Treatment?, N.Y. Times (Mar. 31, 2020), https://www.nytimes.com/2020/03/31/us/coronavirus-covid-triage-rationing-ventilators.html.

• "People with underlying medical problems may get ranked lower, yet low-income people and people of color often have more health problems because they cannot afford topnotch care."

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