

# **COVID-19: Vulnerable Populations and Palliative Care: Call for Social Justice**

**July 9, 2020**

## Part 3 of a 3-Part Series:

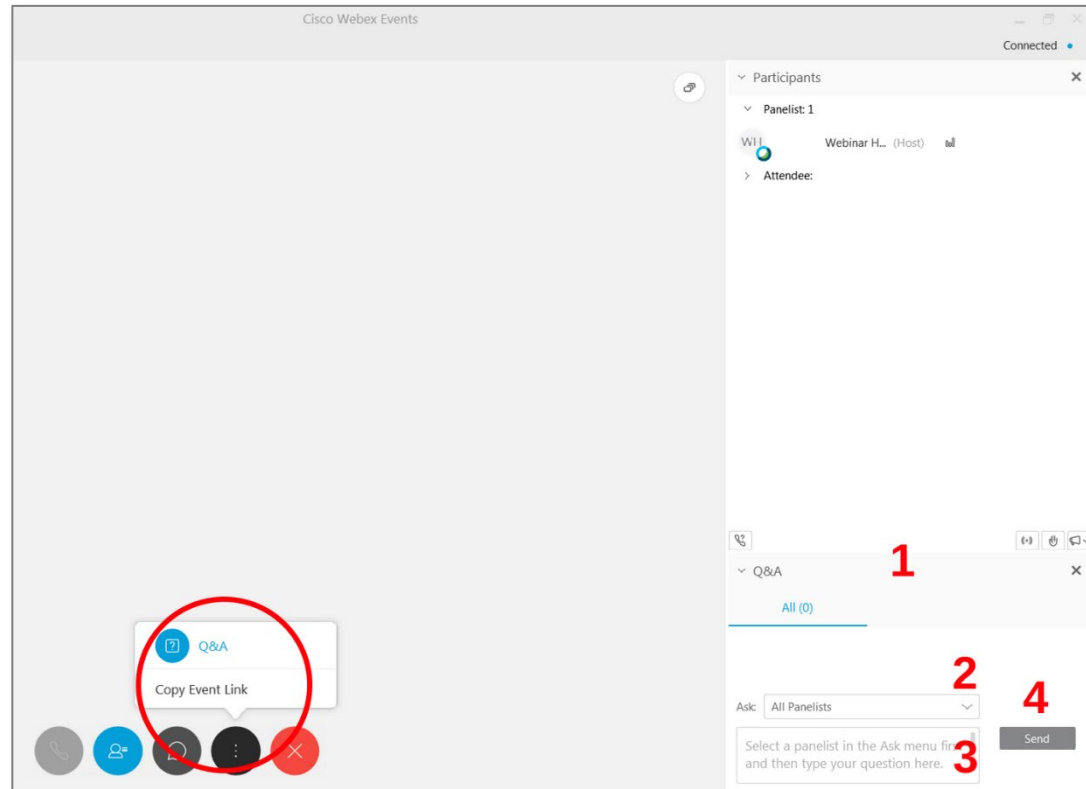


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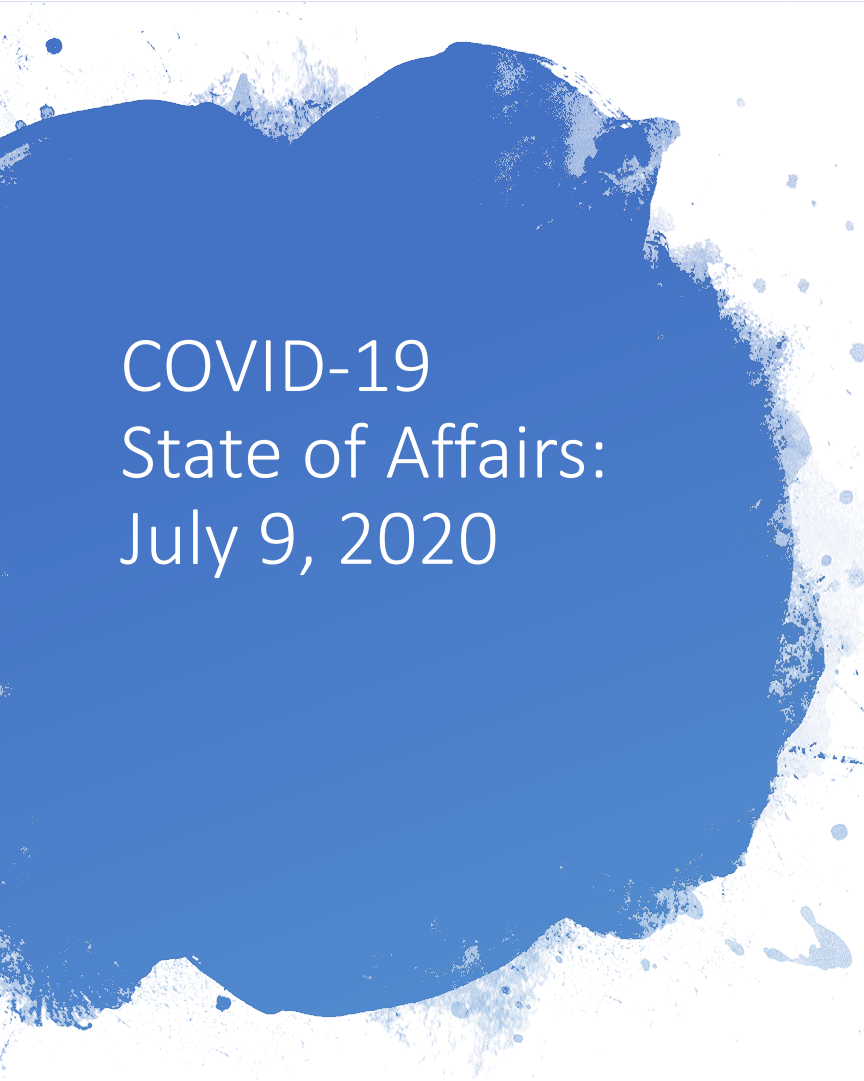


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# Health, Vulnerability and Palliative Care in COVID-19:

*Structural and Human Rights Perspectives*

*Mary Beth Morrissey*



# COVID-19 State of Affairs: July 9, 2020

We are living through and bearing witness to...

- an unprecedented global pandemic;
- uncontrolled U.S. virus spread;
- devastating impacts across diverse and vulnerable populations and communities
  - untold human costs, racial disparities, lost lives, isolation and abandonment, bereavement, moral injury and distress, trauma, unemployment, hunger and homelessness, and other yet unknown consequences; and
- systemic racism exposed by pandemic, growing civil unrest and tragic violence, and overall destabilizing social and economic effects of pandemic

# Focus: Health, Vulnerability and Palliative Care Triad – *Structural and human rights perspectives*

- **Health:** fundamental human right; political, social, economic and environmental conditions and determinants that threaten health and health security (Gostin, 2014) – centrality of *systemic racism*
- **Vulnerability:** risks to health and well being arising from underlying inequities: socioeconomic causes of injury, disease and death, discrimination and forms of racializing or “subhumanizing” people (Teo, 2020); social suffering – *social problems outside the health care sector and health care delivery systems that threaten not only health security, but our very humanity*
- **Human rights:** Mutual, interdependent relationship of right to health and full spectrum of human rights, such as rights to water, food, housing, clean air and built environments (Gostin, 2014); principle of nondiscrimination
- **Ethics:** Right to palliative care; palliative care as public health response to suffering in pandemic crisis conditions, ethics of non-abandonment

# History, Inequities and Disparities

# Understanding social problems: *Theoretical perspectives – racial and social justice*

- Sociopolitical theory: critiques of neoliberalism (Wacquant, 2010; Sugarman, 2015; Morrissey, Lang & Newman, 2019; Founder of neoliberal theory F. Hayek – continued tradition of Adam Smith; [Opinion | The Neoliberal Looting of America - The New York Times](https://www.nytimes.com/2020/07/02/opinion), [www.nytimes.com/2020/07/02/opinion](https://www.nytimes.com/2020/07/02/opinion))
- Public health and human rights theory (Gostin, 2014 – opening webinar in series on June 11th): “*Global health with justice*,” law as public health tool
- Health justice (Sulmasy, 2003); Disability justice (Guidry-Grimes et al, 2020); Environmental Justice (Francis I, 2015)
- Critical theoretical psychology (Teo, 2018; 2020 ); Race theory (Winston, 2004); Critical race theory (Ford et al., 2010); Critical participatory action research (Stoudt, Fox & Fine, 2012)
- Ethics and Bioethics: Disabilities rights, ethical norms (Fins, 2020); Social solidarity, deliberative democracy (Jennings, 2010 ); Phenomenology of older adult suffering (Morrissey, 2012; 2015); Phenomenology of law (Morrissey, 2017); Moral phenomenology and intentionality (Drummond, 2008)

# Minding history: *The Plague of Athens and other disasters and emergencies*

- Bioethicist Joseph J. Fins (2020) compares COVID-19 suffering and loss of *nomos* (i.e., law, rationalism) to the Plague of Athens, as documented by Thucydides in *History of the Peloponnesian War*:

*Thucydides observed, "By far the most terrible feature of the malady was the dejection which ensued when anyone felt himself sickening, for the despair into which they instantly fell took away their power of resistance." As I watch colleagues care for patients without adequate personal protective equipment, I am moved by Thucydides's account of those who cared for the sick during the plague: "[T]here was this awful spectacle of men dying like sheep through having caught the infection from nursing each other. – J.J.Fins, Hastings Center, p. 50.*

- Disasters/emergencies in 21<sup>st</sup> century: Ebola crisis in West Africa (See *Lancet* CDC Ebola Timeline: <https://www.cdc.gov/about/ebola/timeline.html>); 2003 SARS outbreak, influenzas, 2010 Haiti earthquake and tsunamis, Katrina, Maria and Harvey Hurricanes, fires in western states and Australian bushfires; human contributions to climate change and its impacts, including global inequalities, such as scarcity of water (Francis I, *Laudato Si*, 2015).
- COVID-19 exposes pre-existing forms of systemic racism, discrimination, implicit bias and inequities in social determinants, access to care, as well as in health outcomes; current leadership failures and growing civil unrest across the United States

# Snapshot: Global, U.S. and N.Y case and fatality data

- **COVID-19 “perfect storm”:** Global public health crisis, global and United States spread – New York was U.S. epicenter, but new cases spiraling up in other parts of country: Florida, Texas, Arizona and California. Deaths higher than reported. See New York Times, <https://www.nytimes.com/interactive/2020/04/28/us/coronavirus-death-toll-total.html>
  - **Global confirmed cases: Over 12 million** (most rapid virus growth rates in Brazil, US, Peru and Sweden (See NYT, July 6, 2020, <https://www.nytimes.com/2020/07/06/briefing/a-global-comparison-of-coronavirus-cases.html>))
  - **Global deaths: nearing 550,000**
  - **US confirmed cases: over 3 million**
  - **US deaths: nearing 132,000** (dire projections for fall/winter); sharp increase in new cases in south/west
  - **NY deaths: over 32,000**
- (Source: John Hopkins COVID-19 Dashboard: <https://coronavirus.jhu.edu/map.html>)
- **Disproportionate population impacts and intersectionality:** Blacks/African Americans, Hispanics, American Indians, older adults including nursing home residents, pregnant women, health care and frontline workers, low income individuals and those living below poverty line, persons identifying as LGBTQ, persons incarcerated, immigrants, and other vulnerable groups and subgroups – ***cannot afford just treatment to each of these groups today.***



## United States: *Regressive effects of pandemic exacerbated pre-pandemic inequities and injustice*

- Racism, extreme socioeconomic inequalities
- Lack of universal health care
- Minority and low-income populations more likely to have job losses and develop severe infections resulting in hospitalization or death
- Clear relationship between income, education, occupation, social class, sex and race/ethnicity and disease incidence and severity
- Health risk index as function of poverty and percentage of minority population – incidence of risk much higher in poor communities

(Sources: Luiza Nassif-Pires, Laura De Lima Xavier, Thomas Masterson, Michalis Nikiforos, and Fernando Rios-Avila, Levy Economics Institute, 2020; CDC, 2019, “500 Cities: Local Data for Better Health.”)

# CDC Data: *American Indian/Alaska Native disparities*

- **Non-Hispanic American Indian or Alaska Native persons have an age-adjusted hospitalization rate approximately 5.7 times that of non-Hispanic White persons**, non-Hispanic Black persons have a rate approximately 4.7 times that of non-Hispanic White persons, and Hispanic or Latino persons have a rate approximately 4.5 times that of non-Hispanic White persons. Additional data on race and ethnicity by age are available.
- **Some racial and ethnic groups are disproportionately represented among hospitalized cases as compared with the overall population of the catchment area. Prevalence ratios show a similar pattern to that of the age-adjusted hospitalization rates: non-Hispanic American Indian or Alaska Native persons have the highest prevalence ratio**, followed by non-Hispanic Black, and Hispanic or Latino persons
- Inequities in access to water and other social determinants illustrative of burdens on right to health; historical trauma and discrimination; ***“In contrast to personal experiences of a traumatic nature, the concept of historical trauma calls attention to the complex, collective, cumulative, and intergenerational psychosocial impacts that resulted from the depredations of past colonial subjugation.”*** Gone, 2013.

(Source: CDC: <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/pdf/covidview-07-03-2020.pdf>; See Harris, June, 2020, <https://www.eli.org/vibrant-environment-blog/disparity-disease-and-drinking-water-covid-19-and-safe-drinking-water-access-indian-country>; See Gone, 2013, <https://doi.org/10.1177/1363461513487669>)

# COVID-19 Disparities: *New York Study*

“In the population of adult New York residents, through late March 2020, 8.0% of white non-Hispanic, 18.7% of Black non-Hispanic, and 28.4% of Hispanic adults were estimated to have experienced infection with SARS-CoV-2. Compared to white non-Hispanic adults, racial/ethnic minority populations had disproportionately higher per population likelihoods of...

- COVID-19 **diagnosis** (0.93% white non-Hispanic, 1.89% Black non-Hispanic, 1.85% Hispanic),
- **hospitalization** (0.11% white non-Hispanic, 0.50% Black non-Hispanic, 0.48% Hispanic), and
- **death** (0.03% white non-Hispanic, 0.18% Black non-Hispanic, 0.12% Hispanic).”

(Source: Holtgrave DR, Barranco MA, Tesoriero JM, Blog DS, Rosenberg ES, Assessing racial and ethnic disparities using a COVID-19 outcomes continuum for New York State, *Annals of Epidemiology* (2020), doi: <https://doi.org/10.1016/j.annepidem.2020.06.010>.)

# Case example of nursing home residents: *System failures*

- Over 55,000 nursing home resident and worker deaths nationwide, 43% of US death total; 16,432 NY nursing home deaths, 21% of US total; likely significant undercounting, and disproportionately affecting Blacks/African Americans.
- PPE and staffing shortages contributing to neglect
- Failures in reporting and in communicating with families
- Breakdowns in regulatory oversight that mattered, such as how COVID-19 positive nursing home residents accessed care during the pandemic
- ***Human faces***: stories of nursing home residents (and families) abandoned, improperly discharged, not receiving adequate care, heightened risks of abuse and neglect, conditions of confinement and isolation, ***human rights violations, and experience of profound losses, bereavement and trauma***

(Sources: New York State DOH Report (July 2020); New York Times [https://www.nytimes.com/interactive/2020/us/coronavirus-us-cases.html?campaign\\_id=29&emc=edit\\_up\\_20200706&instance\\_id=20053&nl=the-upshot&regi\\_id=69741277&segment\\_id=32708&te=1&user\\_id=6e8449ef70c4ce15f55ec38ace345348](https://www.nytimes.com/interactive/2020/us/coronavirus-us-cases.html?campaign_id=29&emc=edit_up_20200706&instance_id=20053&nl=the-upshot&regi_id=69741277&segment_id=32708&te=1&user_id=6e8449ef70c4ce15f55ec38ace345348); Barnett et al., JAMA, 2020; Henry J. Kaiser Family Foundation. State data and policy actions to address coronavirus. Published June 18, 2020. Accessed June 18, 2020. <https://www.kff.org/health-costs/issue-brief/state-data-and-policy-actions-to-address-coronavirus/>; CMS Medicare Beneficiary Data, July 2020).

# Legal Reforms, Public Health Strategies and Human Rights Frameworks

# Emergency Support for Nursing Homes and Elder Justice Reform Act of 2020

## Introduced by Senator Grassley, Chairman of Senate Finance Committee – key provisions:

- Funding for PPE for nursing home residents and health care workers;
- Reauthorize key provisions of the Elder Justice Act, including funding for adult protective services, long-term care ombudsman programs, and elder abuse forensic centers, and addition of the Federal Emergency Management Agency (FEMA) administrator to the federal Elder Justice Coordinating Council;
- Provisions from the bipartisan Promoting Alzheimer's Awareness to Prevent Elder Abuse Act which would ensure that the Department of Justice's elder abuse training materials take into account individuals with Alzheimer's disease and related dementias;
- Review of Centers for Medicare and Medicaid Services (CMS) Nursing Home Compare site and the CMS nursing home Five-Star Quality Rating System to ensure that the information it contains is up-to-date and accurately reflects the quality of facilities; and
- Creation of "strike teams" to assist nursing homes with performing medical examinations, conducting COVID-19 testing, and implementing of quarantine, isolation, or disinfection procedures.

Source: Robert Blancato, Elder Justice Coalition Summary

# Crisis Standards of Care and Model Law

- Crisis conditions triggered by scarcity – e.g., equipment, ICU beds, PPE, qualified staff
- IOM's Crisis Standards of Care (2012)
  - Legal authority
  - Ethical foundations: duties of fairness, care, stewardship, consistency, proportionality, transparency and accountability
- Uniform ethics/triage guidelines for deciding who gets care
- Model emergency laws (MSEHPA, 2001)
  - PHE planning, declaration and emergency powers
  - Rationing and distribution of health care supplies
  - Vaccination
  - Isolation and quarantine



## CSC: Advance a Systems Framework:

- “...management strategy that recognizes that disparate components must be viewed as **interrelated components of a single system**, and so employs specific methods to achieve and maintain the overarching system. These methods include the use of standardized structure and processes and foundational knowledge and concepts in the conduct of *all related activities*” (George Washington University Institute for Crisis, Disaster and Risk Management, 2009, p. 59).(IOM, 2012, p. 1-3 )

CSC: Ethical justification for palliative care – “Cross-cutting issue”

• **Providing palliative care is an important ethical and medical imperative** ...Setting the expectation that all patients will receive some care, regardless of the availability or scarcity of resources, is an important component of CSC efforts. Incorporating into CSC planning the capabilities necessary to provide palliative care assures the public that even when curative acute care cannot be provided, **every attempt to offer pain management and comfort care to disaster victims will be made**, even if comfort care may mean nonpharmaceutical interventions such as holding a hand or offering words of comfort. (IOM, 2012, p. 1-7)

# Right to Palliative Care: *Moving toward palliative environments*

- Right to palliative care under international conventions
- U.S. Palliative Care (PC): Umbrella that includes both Hospice and Non-Hospice Palliative Care, and a care delivery system and a philosophy of care; hospital-to-community continuum
- Central role in pandemic – *Diane Meier: “secret sauce”*
- *Patchwork quilt* of applicable laws/regulations; unlike Medicare Hospice Benefit, no dedicated financing stream
- **New York PHL**: Palliative Care Information Act (amended 2013): N.Y. PHL Section 2997-c; Palliative Care Access Act: N.Y. PHL Section 2997-d
- Moving beyond palliative medicine to integrated medical and social care, and building palliative environments (Morrissey, Herr & Levine, 2015)

# 73<sup>rd</sup> World Health Assembly: *COVID-19 Response Resolution*

- **73<sup>rd</sup> World Health Assembly**...adopted the **resolution “COVID-19 Response,”** committing governments to deliver palliative care services alongside safe testing and treatment for COVID-19. Governments must pay “particular attention to the **protection of those with pre-existing health conditions, older persons, and other people at risk, in particular health professionals, health workers and other relevant frontline workers.**” ([Operative Paragraph 7.7](#)) The resolution also calls for **equitable access to medicines and vaccines.**

# *Palliative care imperative: what does it look like*

- Access to *integrated medical care and social services and supports* across continuum of care → *hospitals, long term care, community*
- Humanizing medical care through palliative approaches to care → Placing seriously ill and dying people in appropriate, supportive environments and away from overburdened hospitals and institutions; community response/evacuation plans
- Utilizing scarce resources → Transparent, community-based, explicit triage criteria
- Pain is primary symptom in disasters → Access to pain and symptom management; access to essential medicines → stockpiling palliative care medications
- Decision support for patients, families and clinicians → Providing care that patients themselves want, avoiding prolongation of suffering
- Access to generalist level education and training for health professionals, first responders, essential workers and volunteers → competency based
- Community conversations → engage, educate, and prepare the public

# Public Health Strategy for Palliative Care: *Four pillars*

- Policy development
- Policy implementation
- Access to essential medicines
- Education and training

Stjernswärd, Foley, & Ferris, 2007; Morrissey, Lang & Newman, 2019

# NYSBA Health Law Section: *Key Recommendations for New York*

- *After efficacy and safety have been established*, mandatory vaccine, personal medical exemption, prioritizing health care workers
- Review/revise and adopt MSEHPA
- Adopt non-discriminatory Ethics/Triage Guidelines
- Provision of palliative care as ethical minimum when scarce resources
- Review/continue waivers including qualified limited immunities for providers and health care professionals for COVID-19 care, excluding gross negligence
- Evaluate public benefit and costs of reinstating laws waived during pandemic
- Strengthen workforce, educational and childcare systems and protections
- Ensure equitable allocation of resources to vulnerable populations



## Donald Berwick: *"Moral determinants of health" – Envisioning bold future directions*

- *United States: Ratify United Nations human rights agreements*
- *Codify health care as human right*
- *Restore climate change to policy agenda*
- *Prioritize criminal justice system and immigration reforms, hunger and homelessness policies*
- *Re-stabilize US democratic institutions*

(Source: Berwick, JAMA. Published online June 12, 2020. doi:10.1001/jama.2020.11129)

### **Other Lessons Learned:**

- *Invest in public health systems to ensure progressive realization of right to health.*
- *Invest in scientific research to inform evidence-based public policy planning.*
- *Strengthen social bonds, solidarity and shared responsibility for “our common home” (Francis I, 2015)*
- *Strengthen social protections for all people to eliminate inequalities, and reduce poverty and vulnerability across the lifespan (Morrissey, Lang & Newman, 2019).*
- *Eliminate all forms of racism and discrimination.*

# Thank you!

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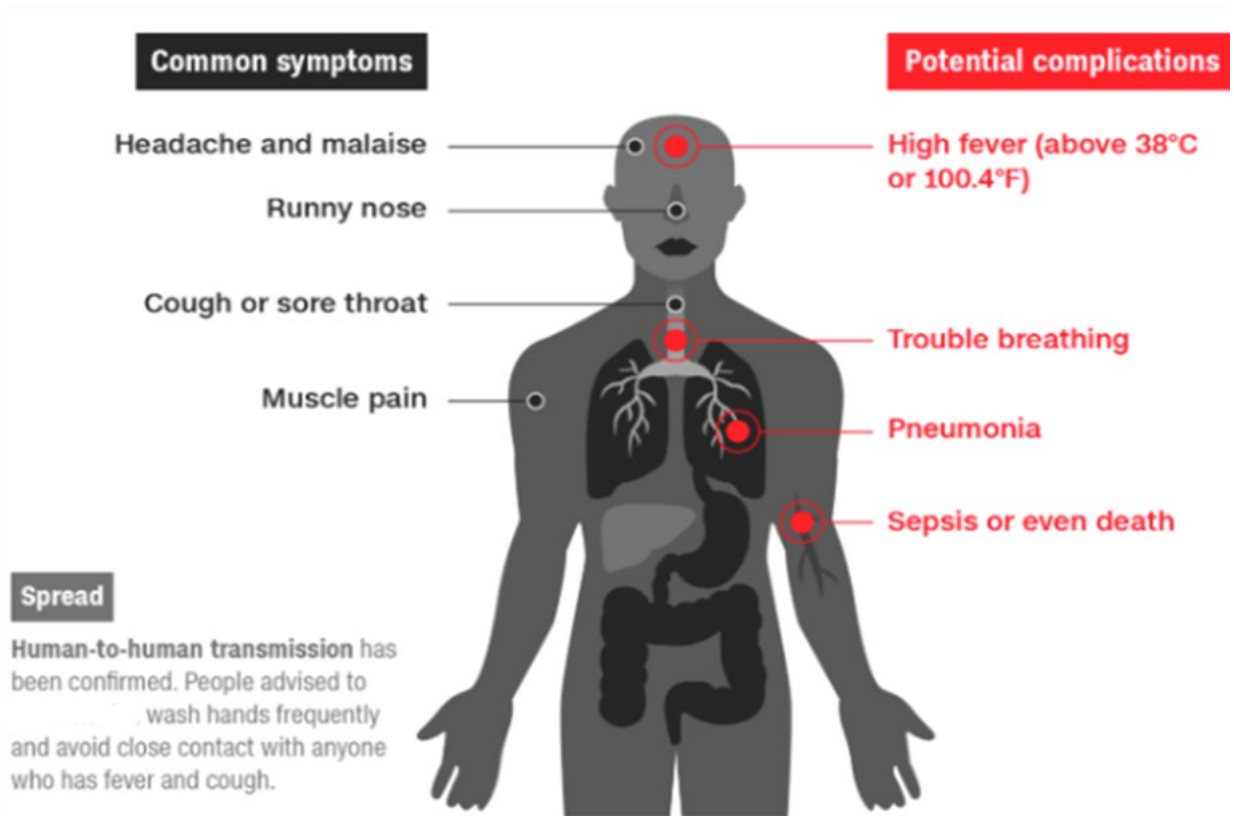
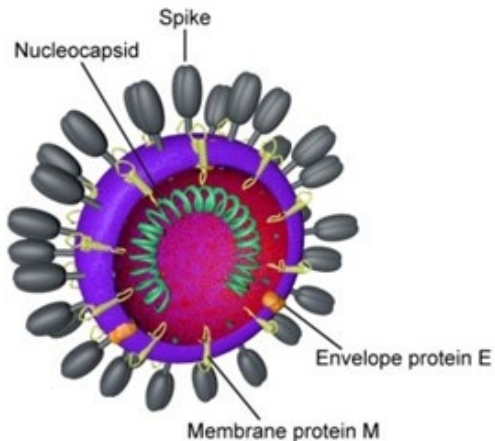
COVID-19

+ Lessons from the Front Lines

Thomas Caprio, MD, MPH, MS

# Novel Coronavirus

- In late 2019 a newly **SARS-CoV-2** coronavirus causing clinical disease named **COVID-19** which started spreading widespread in March 2020



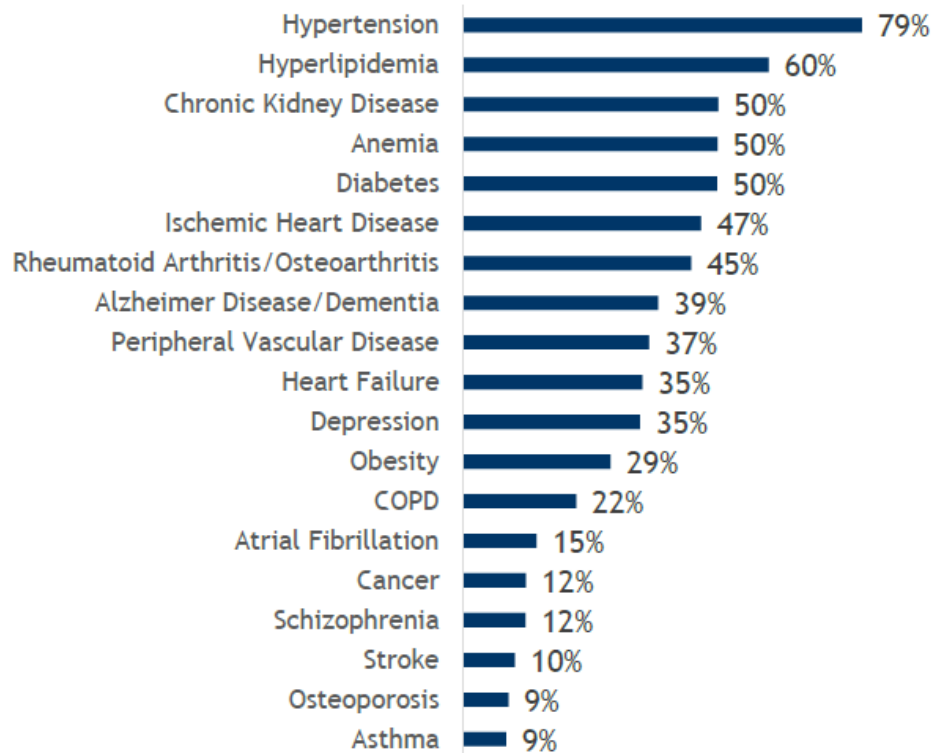
# Preliminary Medicare COVID-19 Data Snapshot:

Medicare Claims and Encounter Data: Services January 1 to May 16, 2020, Received by June 11, 2020

## COVID-19 Hospitalizations

**81,227** Total Fee-for-Service COVID-19 Hospitalizations

### Chronic Condition Prevalence Among Fee-for-Service COVID-19 Hospitalized Beneficiaries



### Medicare Payments for Fee-for-Service COVID-19 Hospitalizations

**\$1.9 Billion**

Total Medicare payment for fee-for-service COVID-19 hospitalizations

**\$23,094**

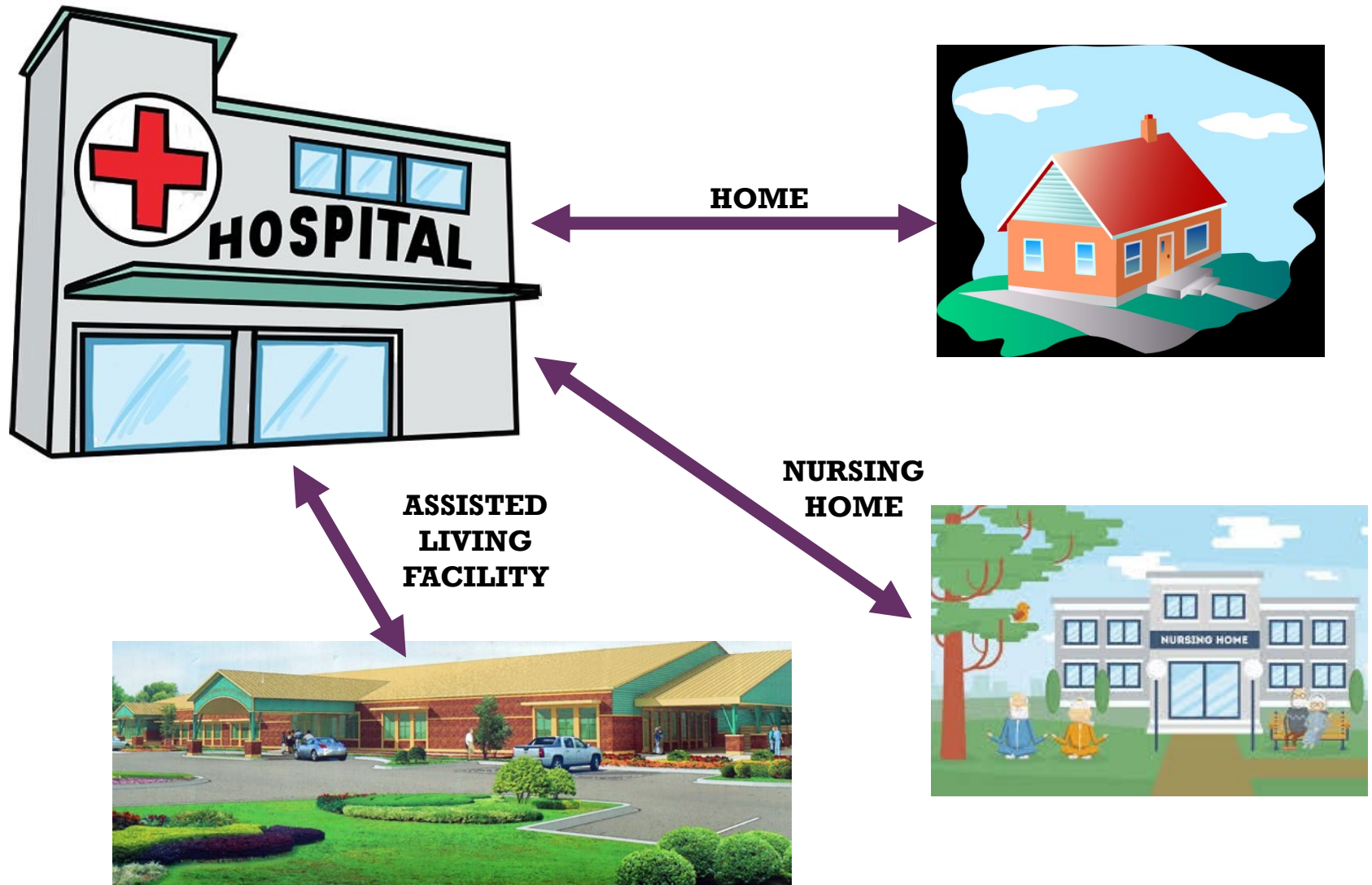
\$5,303 (5<sup>th</sup> percentile) - \$63,721 (95<sup>th</sup> percentile)

Average Medicare payment per fee-for-service COVID-19 hospitalization



**Disclaimer:** All data presented in this update are preliminary and will continue to change as CMS processes additional claims and encounters for the reporting period. COVID-19 hospitalizations are identified using the following ICD-10 diagnosis codes: B97.29 (from 1/1-3/31/2020) and U07.1 (4/1/2020 and after). Medicare claims and encounter data are collected for payment and other program purposes, not public health surveillance, so caution must be used when interpreting the data. For additional details on data limitations, please see page 2 of this data update and view the methodology document available [here](#).

# COVID-19 Admissions and Discharge Planning



# Preliminary Medicare COVID-19 Data Snapshot:

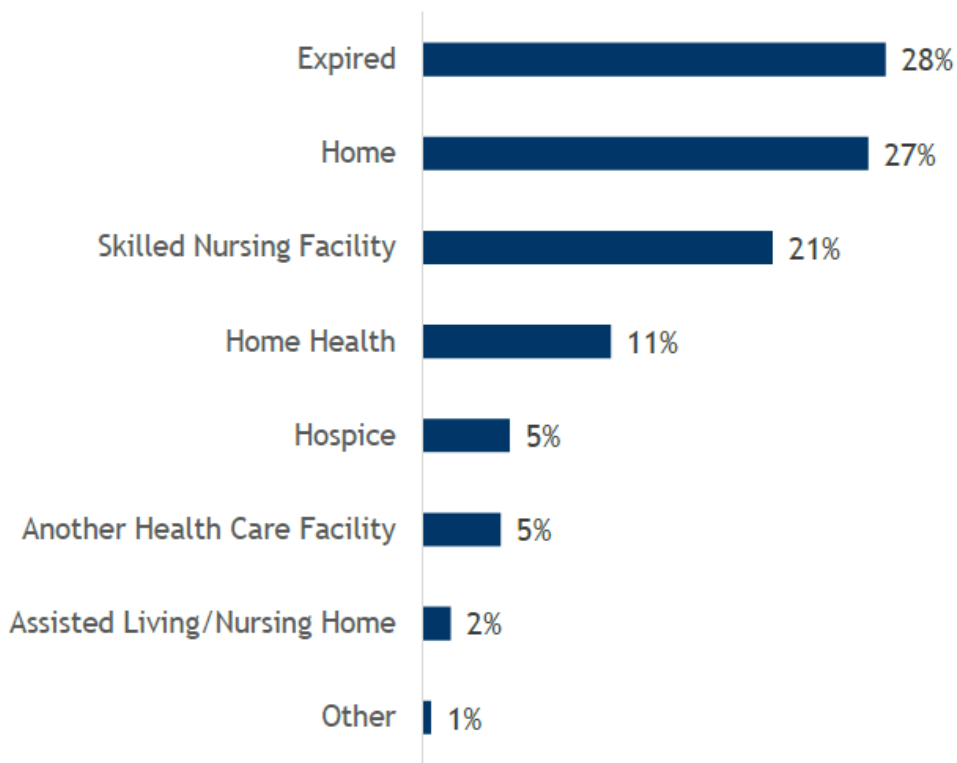
Medicare Claims and Encounter Data: Services January 1 to May 16, 2020, Received by June 11, 2020

## COVID-19 Hospitalizations

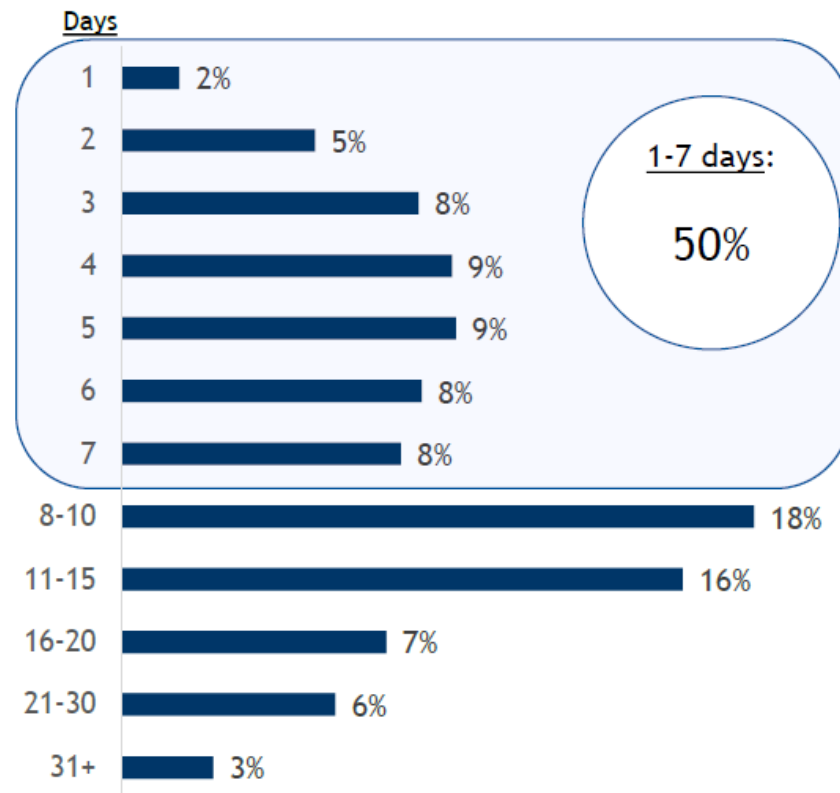
**109,607** Total COVID-19 Hospitalizations

**175** COVID-19 Hospitalizations per 100K

### Percent of COVID-19 Hospitalizations by Discharge Status



### Percent of COVID-19 Hospitalizations by Length of Stay



Note: Percentages may not add to 100% because of rounding.



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# Value of Homecare

## Keeping Patients Safe at Home



- Responding to the needs of ALL patients... “care as usual” for medically fragile.

Meeting the needs of COVID patients

- Hospital Prevention
- Post Hospital – continued care at home
- Leveraging technology... telehealth daily monitoring

Hospice Care – home support for end of life



# Operational Imperatives

## Keep Staff Safe!

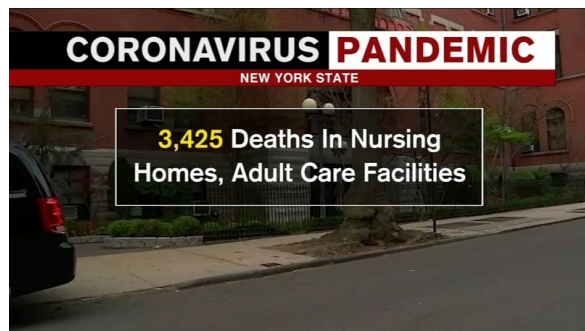


- New Visit Protocols
- Securing Personal Protective Equipment
- Office Stay – Work from Home
- Managing Anxiety



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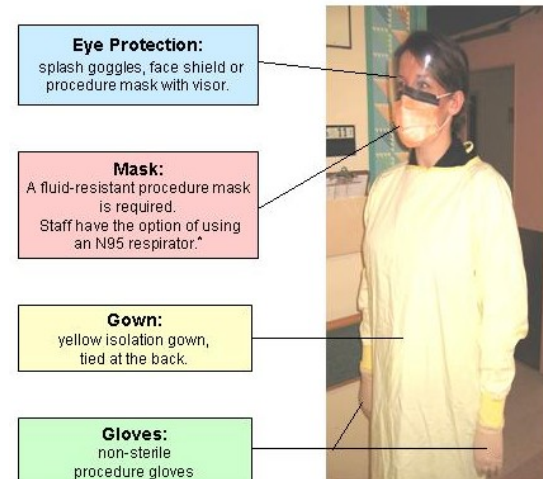
# Challenges of Nursing Homes and Assisted Living Communities



Media Coverage



High Mortality



PPE



Supply & Workforce Shortages

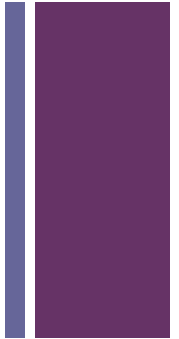


Isolation & Loneliness





# Quality of Care During COVID-19 Crisis

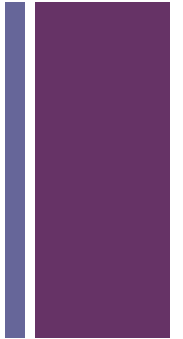


- Palliative and End-of-life (EOL) Care: hospice staff, hospice aides, and chaplains/clergy denied admission to facilities
- Families unable to visit nursing home residents at EOL despite the provision of imminently dying exception
- Workforce shortages affecting ability to respond to resident needs (pain, personal care, falls, incontinence)
- Families/caregivers faced with difficult decisions – where best to have loved-one cared for?
  - All sites of care with unique challenges for visitation and services: hospital, nursing home, assisted living, home
  - Difficulties with travel and risk of infection from COVID-19 high prevalence areas



# Looking Ahead

## Challenges and Opportunities



- Emergency Preparedness
- Viability of long-term care “system” of supports and resources
- New System Collaborations
- Technology (telehealth)
- Research



# **COVID-19: Vulnerable Populations and Palliative Care: Call for Social Justice**

**Geoff-Kagan Trenchardoff**

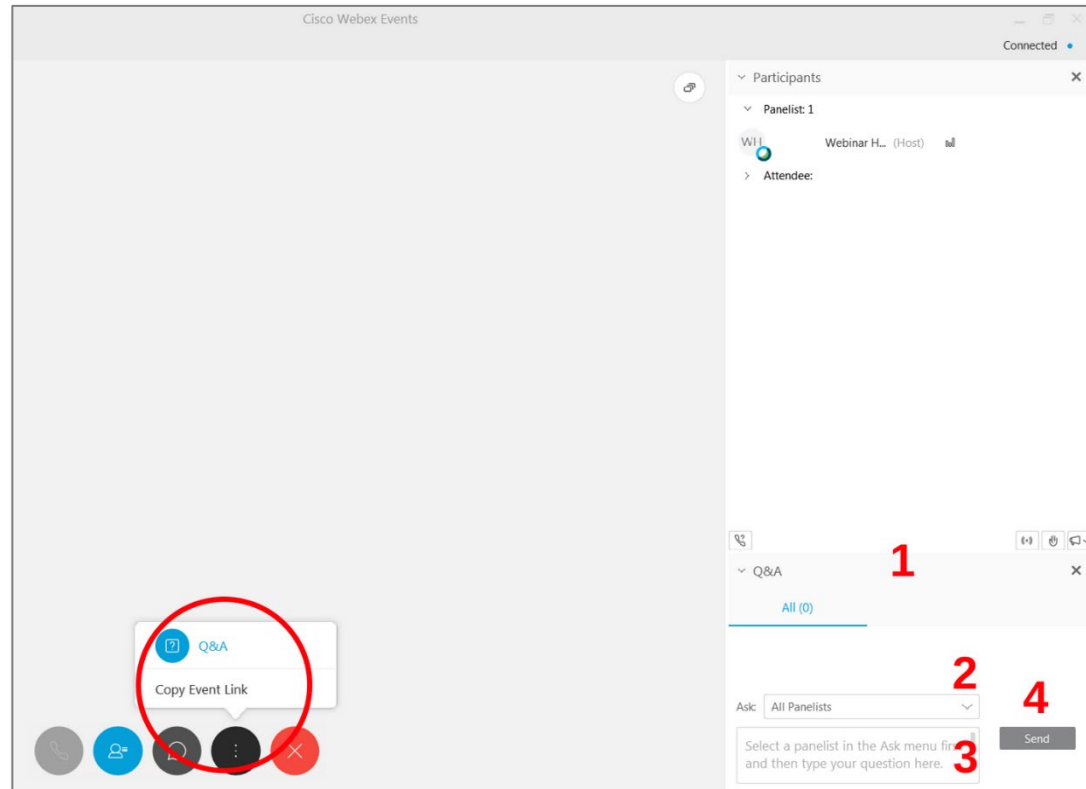


# **COVID-19: Vulnerable Populations and Palliative Care: Call for Social Justice**

**Christopher Comfort**

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July 16, 1 – 2:30pm ET

**COVID-19: Real-Time Guidance, Resources and Information**  
View resources & request assistance at [networkforphl.org/covid19](https://networkforphl.org/covid19)

