

SUDEP in Historically Minoritized Patient Groups: Using Lessons Learned from the COVID-19 Crisis to Develop a Proactive Prevention Model

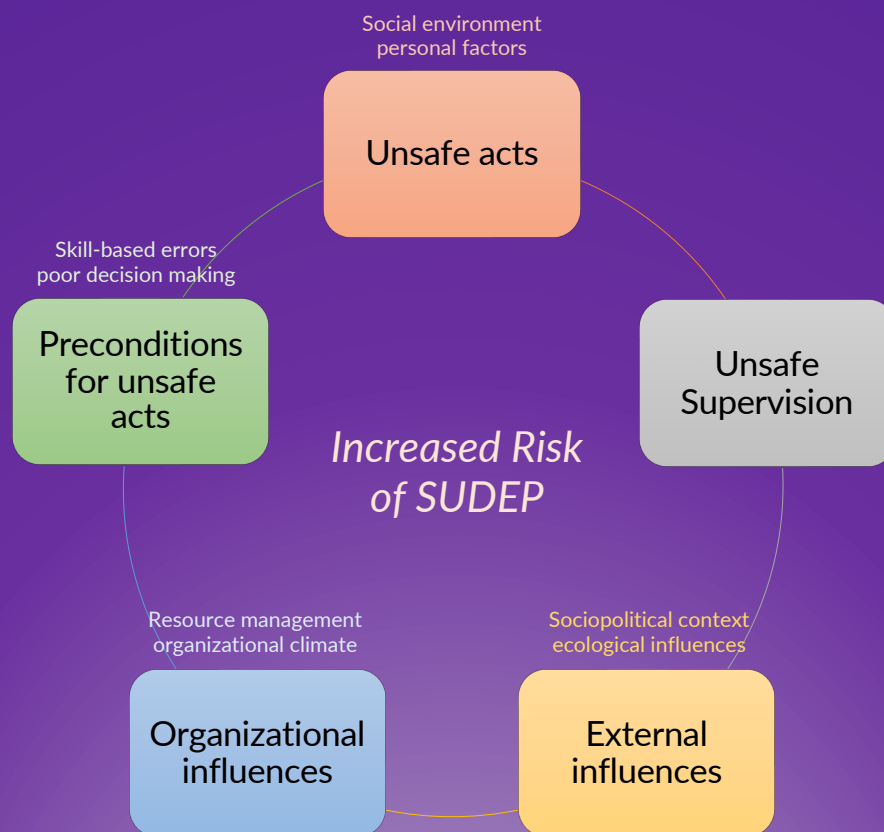


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BACKGROUND:

- Black, Indigenous and People of Color (BIPOC) and economically disadvantaged individuals have markedly elevated risk of developing seizure disorders; group membership is also associated with increased likelihood of mortality due to Sudden Unexplained Death in Epilepsy (SUDEP).
- There is no clear consensus as to a single driver of increased risk of seizure-related disorders in these populations; rather, multi-factorial challenges cited as contributory factors include: access to appropriate epilepsy care/resource scarcity, insurance limitations, reduced health literacy, stigma, historical mistrust of healthcare systems, and/or prior negative patient-provider relations.
- Social and racial factors are shown to be associated with disparate health outcomes in the context of the COVID-19 pandemic; particularly, rates of 'avoidable' patient mortality and morbidity.
- Recent public health research highlights the differences in COVID-19 outcomes among historically marginalized groups, which can be similarly modeled, extrapolated, and applied to better understand the unique and shared risk factors for SUDEP.
- Human Factors Analysis and Classification System (HFACS; Shappell & Wiegmann, 2000), a framework of causality, identifies common factors which result in adverse events or outcomes.
- A recent publication applied the HFACS to examine the public health response to the COVID-19 pandemic (HFACS-Public Health; Bickley & Torgler, 2021)
- Our theoretical investigation critically evaluates specific factors within the structure, culture, governance, and dynamics of the U.S. healthcare system that increases the likelihood of mortality in patients with epilepsy.

We identified potential barriers within the public-health system contributing to the elevated risks of patient mortality from SUDEP



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METHODS & RESULTS:

- A systematic review and critical appraisal was conducted to evaluate the racial/ethnic, sociocultural and socioeconomic disparities in SUDEP, as compared to non-minoritized populations. Variables were informed by the HFACS-PH framework & COVID-19 literature.
- Heterogeneity in outcomes of interests across studies was explored. Differences in characteristics of the studies, methodological diversity or clinical diversity (study populations), were noted. Extracted factors (i.e., age, race, language, level of urbanization and education) were analyzed via the HFACS-PH framework.
- External and organizational influences were predictive of increased SUDEP risk in BIPOC populations.
- Unsafe acts, preconditions for unsafe acts, and unsafe supervision influences were far less represented.

CONCLUSIONS:

- Refining current conceptualizations of SUDEP through a public-health, socio-ecological lens is critical in establishing the causal and contributory pathways with the potential for dire consequences in vulnerable populations.
- We aim to proactively create supportive, preventative recommendations applicable to different levels within the health system, which systematically dismantle modifiable aspects for patient groups who are historically under-represented and underserved.

PROACTIVE PREVENTION TOOLKIT:

- Develop and maintain comprehensive organizational policies to reduce barriers to care and foster equity in BIPOC populations with epilepsy.
- Initiate outreach in areas with higher incidence of minoritized individuals with epilepsy to increase awareness of local resources and specialized healthcare options.
- Explore funding options for future research and implementation related to the modifiable drivers of SUDEP, both including those and beyond factors mentioned here.
- Increase training and informed supervision across health care employees at all levels working with epilepsy patients.



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References

- Bickley, S. J., & Torgler, B. (2021). A systematic approach to public health—Novel application of the human factors analysis and classification system to public health and COVID-19. *Safety Science*, 140, Article 105312.
<https://doi.org/10.1016/j.ssci.2021.105312>
- Shappell, S. A., & Wiegmann, D. A. (2000). *The Human Factors Analysis and Classification System—HFACS*. U.S. Department of Transportation. <https://commons.erau.edu/publication/737>