

New Study Seeks to Better Understand Prolonged Grief Disorder in 9/11 Survivors

Bethesda, Md. – Survivors of sudden and violent deaths, such as those that occurred on 9/11, are at higher risk for prolonged grief disorder (PGD), a newly-defined clinical condition of persistent grief in the Diagnostic and Statistical Manual of Mental Disorders (DSM), defined by profound feelings of loss, significant emotional distress, and changes to a person’s level of functioning. A new collaborative study, led by the Uniformed Services University, will start enrolling subjects this spring to better understand PGD and how grief is impacting quality of life within this population.

Data suggest approximately 15% of those bereaved on 9/11 continue to endorse symptoms consistent with PGD, PTSD, and depression. Despite the fact that more than two decades have passed since this tragedy, few studies have focused on understanding grief responses, how grief is affected by PTSD and depression symptoms, and how this combination of stressors impacts quality of life in this population. This new study, ***Grief and health-related quality of life in WTCHR Survivors: Associations with bereavement, trauma exposures, and mental and physical health conditions***, seeks to do just that.

Participants who lost a loved one on or after 9/11 will be recruited through the World Trade Center Health Registry (WTCHR), which has over 43,000 enrolled individuals who lived or worked in lower Manhattan on 9/11. The study, which will run through the summer of 2025, aims to better understand risk factors for PGD. The researchers will also assess whether those at risk for PGD in this population have access to and use grief-related resources. Participants at-risk for PGD will also have an opportunity to engage in virtual feedback sessions, which will provide them with information about PGD and how to access evidence-based help for their grief.

“We hope to learn who is at risk for PGD and whether those affected are willing and able to engage available evidence-based treatments that can help them,” commented Drs. Stephen Cozza and Joscelyn Fisher, the study’s principal investigators and scientists at the Center for the Study of Traumatic Stress at USU.

“The loss of a spouse, family member, coworker, or acquaintance on 9/11 has been associated with risk for posttraumatic stress and other persistent physical and psychiatric disorders,” Fisher explained.

Multiple traumas and losses are also known to worsen impact on well being, which has been a particular concern given the recent added impact of the COVID-19 pandemic-related deaths. This study will identify risk factors that are related to grief severity and PGD, while also looking at how a history of trauma affects current grief and risk for PGD. Study materials are being translated into Spanish and Chinese to reach a broad and diverse population of participants.

“The objectives of this study are similar to the work we do with bereaved members of our military community,” said Cozza. “Understanding the effects of sudden and unexpected loss in different circumstances will help us better understand how those affected by these types of deaths in all communities can be assisted during such difficult times.”

The study will be conducted in collaboration with the WTCHR, Columbia University's Center for Prolonged Grief, and Voices Center for Resilience. The study is being funded through a Centers for Disease Control and Prevention (CDC) grant.