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World Trade Center Health Program, 2012–2020:

Implications for Clinicians and Health Care Systems

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As a result of the September 11, 2001, terrorist attacks (9/11) in New York City, at the Pentagon, and near Shanksville, Pennsylvania, nearly 3000 people were killed and an estimated 400 000 individuals were exposed to toxin-containing dust, fumes from fires, and debris from damaged and collapsed buildings.[1] In the decade after 9/11, medical care for first responders and other individuals was provided by local public health officials and community health programs.[2] During these 10 years, funding for post-9/11 care was intermittent and uncertain. In 2010, the US Congress began consideration of permanent funding for a health care program for persons involved in rescue, response, recovery, cleanup, and related support activities following the 9/11 attacks (responders), and for persons who were present in the dust or dust cloud on 9/11 or who worked, lived, or attended school, childcare centers, or adult day care centers in the New York City disaster area (survivors).[3,4] On January 3, 2011, President Obama signed into law the James Zadroga 9/11 Health and Compensation Act of 2010, which established the World Trade Center (WTC) Health Program. The program is administered by the director of the National Institute for Occupational Safety and Health in the Centers for Disease Control and Prevention (CDC), US Department of Health and Human Services.

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Human participation protection: The WTC Health Program data used in this article are protected under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which requires the WTC Health Program to maintain the privacy and security of members' personal health information.

The WTC Health Program is authorized to collect, analyze, and report claims data by §3304 of the Zadroga Act (45 CFR part 46.102(l) (2), 21 CFR part 56; 42 USC §241(d); 5 USC §552a; 44 USC §3501 et seq.)

Beginning operations on July 1,2011, the WTC Health Program is a limited federal health care benefits plan covering only those medical conditions that Congress initially deemed WTC-related and other medical conditionssubsequentlyaddedbytheprogramadministrator.[5] Prospective program members need to meet enrollment eligibility criteria related to a 9/11 exposure (ie, activity, location, time of exposure, and duration of exposure).[4] Once the member is enrolled into the program, a comprehensive initial health evaluation is scheduled at one of the program's clinical centers of excellence (CCE) in the New York City metropolitan area or with a clinician or health care organization in the program's nationwide provider network (NPN). During this evaluation, potential WTC-related health conditions are evaluated to determine whether 9/11 exposures were substantially likely to have been a significant factor in aggravating, contributing to, or causing that health condition. If these requirements are met, then the condition is eligible for program certification and is known as a certified WTC-related health condition.

The Zadroga Act also provided funds for research on the physical and mental health conditions that may be related to the 9/11 attacks. In 2020, the WTC Health Program summarized findings from its funded research projects.[6] On September 9, 2021, the CDC released an issue of *Morbidity and Mortality Weekly Report–Surveillance Summary* that describes historical WTC Health Program trends for selected indicators, using administrative enrollment, certification, and medical claims data from 2012 through 2020.[7]

As of December 2020, there were 104 223 enrolled members in the WTC Health Program. Responders represent 73.4% (n = 76 543) of members and survivors represent 26.6% (n = 27 680).[7] The program member population is predominantly male (78.5%), and with a median age increasing over time from 51 years (IQR, 44–57) in 2012 to 59 years (IQR, 52–66) in 2020.[7] General categories of WTC-related health conditions covered by the WTC Health Program (2012–2020) are cancer; aerodigestive conditions such as asthma, interstitial lung disease, and gastroesophageal reflux; musculoskeletal disorders; and mental and emotional health conditions.[7] In 2020, the total number of certified cancers was 20 612 and the total number of noncancer WTC-related medical conditions was 50 611.[7] The most common WTC-related cancers are cancers of the skin, prostate, and female breast.[7] The *MMWR* report highlights that the mean number of WTC-related certified conditions per certified member is 2.7.[7] Furthermore, the report shows that both the enrollment and certification of WTC-related health conditions increased over time (2012–2020) among program members, with the largest increases observed among survivors.[7]

In addition to health conditions covered by the program, members may have other noncovered conditions that affect the WTC-related health conditions covered by the program. Due to the limited coverage formula of the program, non–WTC-related health conditions cannot be covered as in other federal health programs such as Medicare and Medicaid. As a result, care for members with diseases and comorbidities that are not covered must be obtained separately from the program. Separate coverage may complicate patient-centered clinical care for members of the WTC Health Program. However, the program can help coordinate care plans with outside clinicians and health care centers. Clinicians caring for program members will need to determine how best to provide appropriate clinical

care for program members from nonprogram payers given the coverage limitations of the program.

In addition to operating within the constraints of the program's limited care coverage, clinicians caring for WTC Health Program members are also required to adapt their clinical practice to conform to the program's administrative certification requirements. For instance, clinicians need to separate diagnosis and treatment. Once a clinician makes a diagnosis of a WTC-related health condition, that determination must be submitted to the program administrator for certification. Treatment can only be covered by the program when the administrator certifies the condition. Apart from these clinical practice implications, clinicians may also have to navigate providing care to a member who receives care from different CCEs and NPN clinicians or health care organizations in addition to health care plans outside the WTC Health Program.

Similar to other public and private health care plans in the US health care system, future considerations for the WTC Health Program include care factors affecting an aging population. These include development of age-related comorbidities (eg, heart conditions), other chronic diseases, cognitive health deterioration, poly-pharmacy, long-term care needs, and appropriate palliative care and end-of-life care. Future WTC Health Program issues to be addressed include increasing the efficiency and quality of care using technology such as telehealth, lifecycle care management systems, and user-friendly digital health tools to provide feedback to help optimize care. The WTC Health Program will continue to adapt to the changing health care needs of its members and the clinicians who care for them.

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