

An Assessment of Healthcare Access and Utilization in the World Trade Center Health Program

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Objective: Access to healthcare, a national priority, may be better understood through medical surveillance programs like the World Trade Center Health Program (WTCHP). **Methods:** Measures of healthcare access and utilization for 1159 9/11 rescue and recovery workers (“responders”) at the Rutgers Clinical Center of Excellence (CCE) were assessed using negative binomial modeling of the Benefits Eligibility Assessment Screening Tool and compared with 174 9/11 responders in the 2017 New York City Community Health Survey (NYCCHS) using z-testing. **Results:** Approximately 10.8% of Rutgers CCE respondents lacked at least one aspect of healthcare access. Problems accessing healthcare and basic needs were positively associated with CCE utilization and differed between Rutgers CCE and NYCCHS respondents. **Conclusions:** Some 9/11 responders bridge healthcare access gaps via participation in the WTCHP. Surveillance survey tools may help to identify healthcare disparities.

Keywords: general responder, healthcare access, healthcare disparities, medical surveillance, World Trade Center

Healthy People 2030, 10-year national objectives developed by the US Department of Health and Human Services with the goal of improving the health of all Americans, includes access to health services. These objectives include increasing the proportion

of persons with medical insurance and a usual primary care provider, and reducing the proportion of persons who delay or are unable to obtain necessary medical care.¹ Substantial improvements have been observed in these measures, largely associated with expanded state and federal programs; nonetheless, a percentage of people ranging from the high single digits to the low teens still do not meet these basic access to healthcare objectives.^{2,3}

To further understand how federal programs might be associated with access to care, we studied the World Trade Center (WTC) General Responder Cohort (GRC). The WTC-GRC is an open cohort of workers and volunteers who were part of the rescue and recovery effort after the 9/11 attacks on the WTC in New York City. Eligibility criteria for the WTC-GRC include dates, times, duties, and locations worked during the 9/11 response. WTC-GRC members (ie, patients) are eligible for free annual routine monitoring visits which include health, symptom, and health behavior questionnaires, physical examinations, mental health evaluations, laboratory testing, and cancer screenings. Treatment is provided for diagnosed conditions certified as related to the patient’s WTC exposures by the National Institute for Occupational Safety and Health-administered, World Trade Center Health Program (WTCHP) under the James Zadroga 9/11 Health and Compensation Act of 2010.⁴ Monitoring, treatment, and referral services are provided by the WTCHP Clinical Centers of Excellence (CCEs) that include: World Trade Center Health Program at Rutgers, Stony Brook WTC Health and Wellness Program, Northwell WTC Clinical Center, New York University School of Medicine (NYUSOM) Clinical Center of Excellence, and WTC Health Program Clinical Center of Excellence at Mount Sinai.⁵ Program providers at these CCEs function like primary care providers for evaluation and management of certified WTC-related conditions.⁶ As of 2020, the WTCHP includes approximately 60,000 enrolled general responders, a majority of whom live in the New York City Metropolitan area and are assigned to one of the five CCEs.⁵ As part of the monitoring for this program, data are also collected from consenting participants to better understand the exposures, health, and other attributes of this population. Data from the WTC-GRC are managed by the WTC General Responder Data Center (GRDC) at the Icahn School of Medicine at Mount Sinai.

We aimed to learn more about utilization of the CCEs as well as health care access of the WTC-GRC, beyond the monitoring and treatment received through the WTCHP. To better understand overall health care access and potential drivers of CCE utilization, we identified an instrument that captures such information, including: having medical insurance, having a usual primary care provider, and inability to obtain, or delay in obtaining, necessary medical care.

To better understand healthcare access in the WTC-GRC, we aimed to compare it to that of another population similarly exposed to the 9/11 WTC response. This comparison population was selected from the New York City Community Health Survey, an annual survey conducted by the New York City Department of Health and Mental Hygiene, designed to understand health and risk behaviors of adults living in New York City.⁷

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Clinical Significance: Healthcare access inadequacies were associated with increased utilization of the Rutgers Clinical Center of Excellence, suggesting that some 9/11 responders may be bridging healthcare access gaps via participation in the World Trade Center Health Program. Occupational medical surveillance programs offer an opportunity to identify healthcare disparities.

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METHODS

Data Sources

The Benefits Eligibility Assessment Screening Tool

The Benefits Eligibility Assessment Screening Tool (BEAST) was launched by the WTCHP in October of 2017. It is a survey designed to create a customized benefits counseling plan for each enrollee and gathers information to inform the program and enrollees on additional assistance enrollees may be eligible to receive. The questionnaire contains 11 sections: Union Affiliation and WTCHP-Certified Conditions, NYC Law Enforcement Officers and FDNY Firefighters and Fire Officers, DSNY Uniformed Sanitation Workers and Officers, FDNY EMTs, Paramedics, and EMT/Paramedics, NYC and NYS Workers, Non-municipal Workers and Volunteers, Federal Workers, Assessment of Benefits Registration for Members with No Health Conditions, Cancer/Transplant Care Assistance, Care for Non-covered Conditions Assistance, and Social Services Assistance. Each survey is linked to the CCE visit number of the respective respondent and current year at the time of survey administration.

After executing a data use agreement with the GRDC, we were provided de-identified BEAST survey data from October 2017 until May of 2019. The Rutgers CCE was selected for this study because it administered the BEAST nearly continuously since the survey began. We examined only those BEAST questions asked to all or almost all members (See Appendix, <http://links.lww.com/JOM/A848>). We focused on characteristics attributable to healthcare access, including having medical insurance, a primary care provider, and proportion with delayed care. During this time, the Rutgers CCE surveyed 1161 members, yielding a total of 1373 surveys. We included only the 1159 most recent BEAST surveys for each WTC-GRC member; we excluded two WTC-GRC members who declined to complete the BEAST survey.

WTCHP Demographic and Health Data

WTCHP surveys are administered before or during annual monitoring visits to the CCEs. At enrollment, surveys ascertain: demographic information (eg, sex, educational level, family income, race/ethnicity, marital status, parental status, employment status, occupational history, and history of military service); medical history, and diagnoses since their 9/11 response (eg, depression, diabetes, hypertension, GERD, acute and chronic respiratory illness, and cancer diagnosis); health behaviors (eg, tobacco use); and WTC-related exposure (job during 9/11 response and a detailed history of WTC-related exposures that are used to develop a four-level composite variable [low, medium, high, or very high WTC exposure]). Members are entitled to annual monitoring examinations and modifiable factors, including health behaviors and medical history, are reassessed at each follow-up visit. Analyses included only the most recent data obtained for a respective member. Data were received from the GRDC for 40,200 members including 2933 at the Rutgers CCE and 37,267 at non-Rutgers CCEs. All data were from members who consented to have their data aggregated for research.

The New York City Community Health Survey (NYCCHS)

The NYCCHS is a cross-sectional telephone survey with an annual sample of approximately 10,000 randomly selected adults aged 18 and older from all five boroughs of New York City (Manhattan, Brooklyn, Queens, Bronx, and Staten Island). A computer-assisted telephone interviewing (CATI) system is used to collect survey data from selected respondents with landline telephones and cell phones (since 2009).⁷ The 2017 survey contains 23 Sections: Health Status, Access, Cardiovascular Health, Diabetes

and Asthma, Mental Health, Housing, Tobacco, Demographics, Nutrition, Food Insecurity, Physical Activity, Immunizations, International Travel, Cancer, HIV Testing, Sexual Behavior, Alcohol Use, Neighborhood Environment, Justice Involvement, WTCHR, Telephone Module, Geocoding, and Closing.⁸ While a core group of demographic and health topics are included every year, questions related to exposure to the 9/11 response on the WTC were unique to the 2017 version of the survey. Specifically, respondents were asked the following question: from September 11, 2001 to June 30, 2002, did you work at least one shift at the World Trade Center site providing rescue, recovery, clean-up, construction, or support services? The survey includes health care access questions identical or analogous to those of the BEAST, as well as other questions about demographic and clinical characteristics, comparable to data collected by the WTCHP. After executing a data use agreement, New York City Department of Health and Mental Hygiene (NYC DOHMH) provided de-identified NYCCHS data appropriate for comparison of having health insurance, having a primary care provider, having forgone needed medical attention in the past 12 months, and basic needs insecurity.

Data Analysis—Rutgers CCE Healthcare Access and Utilization

We assessed the relationship between key healthcare access variables along with other potential drivers of utilization measured by the BEAST (eg, food insecurity, union membership, chronic disease states) and CCE utilization. The primary outcome was CCE visit intensity, defined as the member's cumulative count of visits at any CCE, including both monitoring and treatment visits, and interpreted as an indicator of CCE utilization. The distribution of the CCE visit intensity among BEAST respondents was right skewed (mode of 1, mean of 5.55, and variance of 14.90), so we used a negative binomial multivariable model to assess CCE visit intensity for BEAST questions asked of the Rutgers CCE attendees. We employed a negative binomial model rather than a Poisson model because of over dispersion of the outcome. We omitted diagnosis with a 9/11-related condition due to high correlation with having a certified condition.

Data Analysis—Comparison of Rutgers CCE Members to Those Attending the Other Four CCEs

The GRDC generated descriptive statistics for demographics and health variables stratified by the Rutgers CCE and non-Rutgers CCEs comparing Rutgers CCE members to the larger pool of CCE members. We assessed differences of demographic and health status variables between the Rutgers CCE and non-Rutgers CCE members using two-tailed z-testing. Most demographic and health status variables were dichotomized due to small numbers in one or more categories.

Data Analysis—Comparison of Healthcare Access and Utilization Between the WTC-GRC and NYCCHS

We assessed differences between Rutgers CCE members responding to the BEAST from October 2017 to May 2019 and WTC-exposed individuals captured by NYCCHS in 2017 in having health insurance, having a primary care provider, having forgone needed medical attention in the past 12 months, and basic needs insecurity using two-tailed z-testing.

Data Analysis—Comparison of Demographic and Clinical Characteristics of WTC-GRC and NYCCHS

We assessed differences in demographic and health variables between all CCE members, as of June 4, 2019, and WTC-exposed populations captured by NYCCHS in 2017 using two-tailed z-testing. We included the following variables: sex, race, education,

TABLE 1. Responses to the BEAST* Survey; Rutgers Clinical Center of Excellence Patients from October 2017 until May 2019 (n = 1159)

	n	Percent
Health access and economics		
Currently have health insurance	1137	98.1%
Have a primary care provider	1072	92.5%
Currently have problem accessing health care for conditions not covered by the WTCHP	32	2.8%
Either lacking health insurance, without a primary care provider, or having a problem accessing healthcare	125	10.8%
Having trouble paying for basic needs (shelter, utilities, food, or transportation)	42	3.6%
Union membership		
Currently	573	49.4%
During WTC response	860	74.2%
WTC response and health		
Have ≥1 WTCHP-certified physical health conditions	759	65.5%
Been diagnosed with a WTC-related physical or mental health condition	973	84.0%
Employed by New York City during WTC response	366	31.6%
Diagnosed with cancer since 9/11	299	25.8%
Had or are awaiting an organ transplant	13	1.1%

*BEAST: The Benefits Eligibility Assessment Screening Tool.

income, marital status, working status, history of smoking, perceived health, high blood pressure diagnosis, diabetes diagnosis, and depression diagnosis. Most demographic and health status variables were dichotomized due to small numbers in one or more categories.

Human Subjects

This study (ID: Pro2019000952) was determined to be exempt from review by Rutgers, The State University of New Jersey, Biomedical and Health Sciences Institutional Review Board.

RESULTS

Rutgers CCE Healthcare Access and Utilization

Approximately 10.8% of respondents reported lacking at least one aspect of healthcare access (Table 1). Many respondents reported current (49.4%) or prior union membership (74.2%). A majority of respondents reported a WTC-related condition (84.0%), most of which had been certified by the WTCHP (65.5%). Having one or more WTCHP-certified physical health

conditions was positively and significantly associated with having had more than twice (110%; *P* < 0.0001) the number of CCE visits, compared to members without a certification (Table 2). A history of cancer diagnosis was significantly associated with 25% (*P* < 0.0001) fewer CCE visits. Members who had a history of employment with New York City had a significantly higher number of CCE visits (8%). Problems accessing medical care not covered by the WTCHP and trouble paying for basic needs were positively associated with more CCE visits (13% and 9%, respectively).

Comparison of Rutgers CCE Members to Those Attending the Other Four CCEs

Compared with non-Rutgers CCE members, a higher proportion of Rutgers CCE members were men (92.4% vs 85.8%), Caucasian (84.3% vs 64.7%), higher-earning (58.1% vs 48.4% earning over \$70,000), and married/partnered (79.3% vs 71.7%) (Table 3). There were also some differences in terms of risk factor histories with a higher proportion of Rutgers CCE members having had employment history of non-combat military experience (24.0%

TABLE 2. Rutgers Clinical Center of Excellence Visit Intensity Association with BEAST* Survey Responses; October 2017 until May of 2019, Estimated Using Negative Binomial Regression

	Coefficients (95% CI)	P-Value (Pr > ChiSq)
Intercept	0.90 (0.65, 1.16)	<0.001
Health access and economics		
Currently have health insurance	0.00 (-0.25, 0.24)	0.994
Have a primary care provider	-0.03 (-0.16, 0.10)	0.649
Currently have problem accessing health care for conditions not covered by the WTCHP [†]	0.13 (-0.07, 0.32)	0.214
Having trouble paying for basic needs (shelter, utilities, food, or transportation)	0.09 (-0.09, 0.27)	0.326
Union membership		
Currently	-0.02 (-0.09, 0.06)	0.674
During WTC response	0.04 (-0.05, 0.14)	0.351
WTC response and health		
Have ≥1 WTCHP-certified physical health conditions	1.10 (1.02, 1.18)	<0.001
Employed by New York City during WTC response	0.08 (0.00, 0.16)	0.043
Diagnosed with cancer since 9/11	-0.25 (-0.33, -0.17)	<0.001
Had or are awaiting an organ transplant	0.05 (-0.25, 0.35)	0.747

*BEAST, Benefits Eligibility Assessment Screening Tool.

[†]WTCHP, World Trade Center Health Program.

TABLE 3. Descriptive Statistics of the WTCHP* General Responder Cohort†

	Rutgers CCE		Non-Rutgers CCEs		P-Value
	n = 2,933	Mean (sd)	n = 37,267	Mean (sd)	
Age on 9/11/2001	2,933	39.3 (8.8)	37,266	38.3 (8.8)	<0.001
	n	Percent	n	Percent	P-Value
Male	2,710	92.4%	31,963	85.8%	<0.001
White (Non-Hispanic)/Caucasian	2,429	84.3%	23,905	64.7%	<0.001
Any college	1,574	58.0%	20,250	56.8%	0.234
Income of ≤\$70,000	865	41.9%	14,308	51.6%	<0.001
Married or partnered	2,299	79.3%	26,510	71.7%	<0.001
Has children	402	80.6%	6,856	76.7%	0.044
Working full time	1,976	73.7%	26,535	73.9%	0.795
Has ever served in law enforcement	864	63.3%	13,493	70.7%	<0.001
Served in law enforcement on 9/11	1,294	46.5%	19,374	52.8%	<0.001
Has ever served in military (combat/war zone)	121	12.0%	1,292	10.0%	0.043
Has ever served in military (NOT combat/war zone)	256	24.0%	2,543	19.0%	<0.001
Intermediate or low composite 9/11 exposure	2,136	79.4%	28,492	79.5%	0.904
Has ever been a smoker	659	39.0%	9,523	38.8%	0.873
Perceived health: good or better	1,331	63.3%	19,578	66.2%	0.007
Hypertension	1,342	49.0%	16,602	45.8%	0.001
Depression	252	12.4%	3,355	11.8%	0.418
Diabetes	393	14.4%	5,562	15.4%	0.162
Chronic obstructive pulmonary disease (COPD)	423	15.6%	4,775	13.3%	0.001
Gastroesophageal reflux disease (GERD)	1,379	50.6%	16,337	45.4%	<0.001
Apnea	964	43.8%	9,456	32.3%	<0.001
History of a cancer diagnosis	661	25.3%	6,791	19.3%	<0.001

*WTCHP: World Trade Center Health Program.

†Members assigned to one of the five Clinical Centers of Excellence as of June 4, 2019 and consented to have their data aggregated on at least one visit.

vs 19.0%), and not having been employed in law enforcement during their 9/11 response (53.5% vs 47.2%) or ever (36.7% vs 29.3%). Health status characteristics substantially differed in that a higher proportion of Rutgers CCE members were diagnosed with GERD (50.6% vs 45.4%), sleep apnea (43.8% vs 32.3%), and cancer (25.3% vs 19.3%).

Comparison of Healthcare Access and Utilization Between the Rutgers CCE and NYCCHS:

Rutgers CCE members who completed the BEAST differed substantially from the 9/11 responder subgroup of the NYCCHS in terms of healthcare access and basic needs security (Table 4). Rutgers CCE members had similar rates of having health insurance (98.3% vs 94.2%) and having a primary care provider (93.8% vs 90.8%), when compared with the NYCCHS subgroup. Rutgers CCE members were substantially more likely to have obtained needed

medical care within the past 12 months (96.9% vs 86.6%) and have food security (95.8% vs 89.1%).

Comparison of Demographic and Clinical Characteristics of the Rutgers CCE and NYCCHS

Members of the Rutgers CCE and the 9/11 responder subgroup of the NYCCHS were similar in terms of age at 9/11, diagnosed depression, and diagnosed diabetes (Table 5). However, they differed in that a higher proportion of Rutgers CCE members were men (92.4% vs 66.1%), Caucasian (84.3% vs 42.0%), higher-earning (58.1% vs 31.3% earning over \$70,000), married/partnered (79.3% vs 45.7%), working (73.7% vs 63.2%), and had not attended college (58.0% vs 69.5% with any college). Exposure characteristics differed in that a lower proportion of Rutgers CCE members were smokers (39.0% vs 50.0% ever smokers). Health status characteristics differed in that a higher proportion of CCE members were told they have high blood pressure (49.0%

TABLE 4. Comparison of Access to Healthcare and Basic Needs Between the 9/11 Responder Subgroup of NYCCHS* (2017) and 9/11 General Responders Served by Rutgers Clinical Center of Excellence in WTCHP† (BEAST Respondents from October 2017 until May 2019)

	NYCCHS		Rutgers CCE		P Value
	n	Percent	n	Percent	
Has health insurance	161	94.2%	1137	98.1%	0.002
Has a primary care provider	158	90.8%	1072	92.5%	0.437
Forgone needed medical attention in the past 12 months	23	13.4%	32	2.8%	<0.001
Basic needs insecurity‡	19	10.9%	42	3.6%	<0.001

*NYCCHS: The New York City Community Health Survey.

†WTCHP: World Trade Center Health Program.

‡Insecurity includes only food insecurity for NYCCHS population.

TABLE 5. Comparison of Demographics and Health Variables Between the 9/11 Responder Subgroup of NYCCHS* (2017) and 9/11 General Responders Served by Rutgers Clinical Center of Excellence in WTCHP†

	NYCCHS Respondents		Rutgers CCE Respondents		P-Value
	n	Mean	n	Mean (SD)	
Age on 9/11 (years)‡	173	38.4	2,933	39.3 (8.8)	0.919
	n	Percent	n	Percent	P-Value
Male	115	66.1%	2,710	92.4%	<0.001
White (non-Hispanic)	73	42.0%	2,429	84.3%	<0.001
Any College	121	69.5%	1,574	58.0%	0.013
Income ≤\$70,000					
FPL minimum estimate§	125	71.8%	865	41.9%	<0.001
FPL maximum estimate§	114	65.5%	865	41.9%	<0.001
FPL midpoint estimate§	119.5	68.7%	865	41.9%	<0.001
Married or partnered	79	45.7%	2,299	79.3%	<0.001
Working	110	63.2%	1,976	73.7%	0.016
Has ever been a smoker	87	50.0%	659	39.0%	0.049
General health perceived as good or better	126	73.3%	1,331	63.3%	0.026
High blood pressure	70	40.2%	1,342	49.0%	0.152
Diabetes	30	17.2%	393	14.4%	0.671
Depression	18	11.0%	252	12.4%	0.859

*NYCCHS: The New York City Community Health Survey.

†WTCHP: World Trade Center Health Program.

‡Imputed using average of highest and lowest estimate for provided age ranges.

§NYCCHS income statistics imputed using highest, lowest, and midpoint estimates of NYCCHS Federal Poverty Level (FPL) range data, in conjunction with respective family size and 2017 FPL tables.

vs 40.2%) and had lower perceived levels of health (36.7% vs 26.7% rating health as fair or poor).

DISCUSSION

We observed high rates of overall healthcare access across the Rutgers CCE population, which is encouraging for the positive roles that the Rutgers CCE and the WTCHP play in these patients’ lives. As would be expected, having a WTCHP-certified related condition, for which a CCE will provide cost-free surveillance and treatment, was strongly associated with CCE utilization at the Rutgers CCE. The inverse association with CCE utilization at the Rutgers CCE for those with a cancer diagnosis history could be related to early referral for a certified cancer condition and subsequent management by a specialist provider rather than the CCE. Inadequate access to healthcare for non-certified medical conditions and basic needs insecurity were positively associated with CCE utilization at the Rutgers CCE; as such a CCE may be serving as a safety net for surveillance and treatment of a certified condition that might otherwise be managed by a patient’s own private medical providers.

When comparing a CCE patient population with a subgroup of city-wide residents included in the NYCCHS, one would expect the CCE patient population to be a sicker group, consistent with our findings. Differences in healthcare access between BEAST respondents of the Rutgers CCE and the 9/11 responder subgroup of the NYCCHS identified healthcare disparities between these two groups. However, this is not surprising since these groups differed in terms of demographic characteristics typically associated with healthcare access (sex, income, race/ethnicity, and marital status).^{9,10} It is concerning that nearly one in seven of the 9/11 responders surveyed by the NYCCHS had missed out on necessary medical care within the prior year. Further outreach to 9/11 responders in the New York City Metropolitan Area may be warranted to ensure that all have been offered at least one screening examination from the WTCHP. Screening tools like the BEAST offer an ongoing opportunity for medical surveillance programs

such as the WTCHP to better identify healthcare access gaps and resources available to overcome such gaps. Ultimately, such efforts serve to better understand and address healthcare access disparities.

Limitations

This study was conducted using one of the five CCEs, Rutgers CCE, and as such may not be generalizable to the other CCEs. Rutgers CCE members were more likely to be men, Caucasian, wealthier, married/partnered, and sicker than non-Rutgers CCE members. These differences may drive different utilization patterns for the non-Rutgers CCEs. Further study of all BEAST data obtained from all CCE sites would confirm whether the observed relationships extend beyond the Rutgers CCE.

Comparison of the 2017 NYCCHS data with BEAST data that span multiple years (from the time of launch in October 2017 until May 2019) could be a concern if changes in healthcare and access had occurred during that time interval. However, there were few differences in questions across surveys and these were limited to a small minority of questions (survey questions for the NYCCHS and BEAST used in this analysis are listed in the Appendix, <http://links.lww.com/JOM/A848>).

The NYCCHS subgroup was an imperfect control group for comparison to Rutgers CCE members; while more than 10% of Rutgers CCE members live in New York City and many live in areas of New Jersey very close to New York City, a substantial portion of Rutgers CCE members do not live near New York City. We also do not know the extent to which the NYCCHS and Rutgers CCE respondents are similar in terms of their World Trade Center Response exposures. However, the extensive data derived from the NYCCHS were not available for a population more similar to Rutgers CCE members. Furthermore, it is certainly possible that some of the 9/11 responder subgroup of the NYCCHS are also enrolled in the WTCHP and members of one of the CCEs. However, any such overlap would be expected to reduce differences between the two samples and diminish the statistical significance of the many differences found.

CONCLUSION

Our findings suggest that 9/11 responders with inadequate overall healthcare access may be bridging some access gaps via participation in the World Trade Center Health Program (WTCHP) and that health and healthcare disparities may exist between participants and non-participants of the WTCHP. These findings inform administration of occupational medical surveillance programs as well as offer an opportunity to identify healthcare disparities, such as healthcare access, in surveyed populations.

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