

Research Article

A Qualitative Analysis of New York City Based Primary Care and Specialty Providers' Knowledge of 9/11-Related Health Conditions and Health Care Services

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Abstract

Introduction: More than 10 years after 9/11, thousands of directly exposed persons have myriad disaster-related physical and mental health conditions. Previous studies suggest affected persons may not be utilizing any of the health programs that were created expressly to address 9/11-related health conditions due, in part, to a lack of referrals from primary care physicians.

Aim: To understand providers' knowledge of 9/11-related medical conditions, views on and referrals to 9/11 health programs, and how best to provide educational resources to providers and patients.

Methods: We conducted semi-structured in-depth individual telephone interviews with 20 New York City based primary care and relevant specialty providers. The interviews were recorded, transcribed and inductively open-coded for thematic analysis.

Results: Providers were fairly knowledgeable about psychiatric and respiratory conditions commonly associated with 9/11, but less so regarding conditions whose relationships to 9/11 are still under investigation. Most providers considered 9/11 exposure an important part of patients' medical histories, but did not typically screen for exposure, believing patients would self-report exposure or that exposure was no longer relevant. The majority of providers had positive perceptions of the 9/11 programs, though only some had referred their patients. Providers expressed interest in learning more about 9/11-related health programs and conditions.

Conclusion: NYC based medical providers are an under-utilized source of referrals to the 9/11 health programs. Furnishing providers with detailed information on program locations, eligibility requirements, services, and advantages along with summaries of 9/11 research and patient educational materials may increase provider referrals to the programs.

Keywords: 9/11; World Trade Center; World Trade Center Health Program; Disaster health; Disaster preparedness; Medical providers; Qualitative interviews

Background

More than a decade after September 11, 2001 (9/11), persons directly exposed to the World Trade Center (WTC) attacks continue to demonstrate disaster-related physical conditions, including asthma, shortness of breath, persistent cough and wheezing, gastroesophageal reflux disease, and mental health conditions such as posttraumatic stress disorder (PTSD) and depression [1-8].

While some programs were providing services as early as 2001, the WTC Health Program (WTCHP) for survivors and responders began in July, 2011 as part of the federal James Zadroga Health and Compensation Act of 2010 [9]. In order to provide sustained screening, monitoring, and treatment of 9/11-related physical and mental health conditions, services are available to those impacted by the WTC disaster currently residing in New York City (NYC) or nationwide. Services are provided at no out-of-pocket cost to eligible individuals who either resided, worked, or were present in lower

Manhattan on 9/11 (survivors) or who served as rescue, recovery, and clean-up workers and volunteers (responders) [10]. The WTCHP clinical services are provided in the NYC metropolitan area at NYC Health and Hospital Corporation's WTC Environmental Health Center (EHC) for survivors, and the General Responder Consortium or the WTC Medical Monitoring and Treatment Program of the Fire Department of New York for responders. For persons living outside the NYC metropolitan area, services are provided by a nationwide network of providers.

Studies attributed the observed relatively low mental health service utilization in the six months following 9/11 to inadequate finances or time, beliefs that others are in greater need of services or that individuals can care for themselves, mistrust of mental health professionals, and fear of discussing the attacks [11-13]. In focus groups conducted several years after 9/11, enrollees in the WTC Health Registry (Registry), a cohort study of 71,431 persons with firsthand exposure to the WTC attacks in NYC, mentioned numerous

Table 1: Interview topics and sample questions.

| Topic | Sample Questions |
|-----------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Background | <ul style="list-style-type: none"> • How long have you been practicing medicine? In NYC? • What area(s) do you specialize in? • Is there a particular population you treat? (e.g., children, geriatrics, low-income) |
| General 9/11 Knowledge | <ul style="list-style-type: none"> • As far as you know, what are some medical conditions associated with 9/11? • How did you find out about these conditions/where would you go to find out information about 9/11-related conditions? (e.g., nyc.gov, WTC Health Registry, 9/11 health website, etc.) • List of specific conditions |
| Patient Treatment and Education | <ul style="list-style-type: none"> • How important is it to know whether or not your current patients were exposed to the events surrounding 9/11? • Do you screen for this information? • Have you experienced any challenges discussing potential 9/11-related issues or conditions? • How would knowledge of a patient's 9/11 exposure change your overall evaluation/treatment plan? |
| 9/11 Program Referrals and Provider Awareness | <ul style="list-style-type: none"> • Are you aware of any specialty providers for 9/11-related health conditions? • Have you ever referred patients who have exhibited 9/11-related physical (or mental) conditions to other services? Why or why not? • How would you feel if a patient requested a referral to a 9/11 specialty program? • List of programs • In your opinion, what are some of the ways that organizations could better reach providers like yourself to provide you with more information on 9/11 health, the programs, and educational materials for your patients? |

programmatically and personal barriers to care, including limited knowledge of 9/11-related health conditions and lack of awareness of 9/11-related health care programs, as well as perceived stigmatization of receiving mental health care, complicated intake procedures, long waiting lists, and delays in scheduling an appointment [14].

Findings from these focus groups also indicated that primary care providers (PCPs) can play an important role in connecting survivors and responders to 9/11-related specialty care. Participants reported having strong and enduring relationships with their PCPs, and indicated that a lack of referral from their PCP to the programs was one reason why they had not sought services in the past. Participants were also reluctant to seek care from a provider they were concerned would feel like a 'stranger' [14].

A recent study examining trends in physician referrals from 1999-2009 in the United States found that the overall probability that a physician visit would result in a referral to another provider increased by 94% over the 10 year period [15]. It is suggested in the biomedical literature that successful patient referrals to specialists require endorsement from the PCP, an understanding of the referral's purpose by the patient, and coordination between the patient, their PCP, and the specialist [16,17].

Based on the Registry focus group findings, it is evident that PCPs are likely to be a key component of engaging exposed persons in 9/11-related specialty care. The purpose of this study is to understand 1) provider knowledge about 9/11-related medical conditions; 2) how providers currently view 9/11-related health care services (WTC Health Program); 3) motivation to refer patients to the WTC Health Program; and 4) the best methods of engaging providers and providing educational resources.

Methods

Interviews were conducted with 20 NYC-based health care providers (18 physicians, 1 psychologist, and 1 physician's assistant) from June through August of 2013. Recruitment, interviews, and transcription were performed by an outside vendor. A list of potential providers was created, from a variety of sources including the vendor's database (n=80), online search engines and New York registries (n=361), and physicians identified by the Registry (n=8).

The list was reviewed to ensure there was only one provider from each entity, and then randomized for systematic calls. To be eligible for the study, providers had to be practicing currently and have their primary practice in NYC. Upon initial contact (n=347), providers were screened for interest and eligibility to participate in the interviews (n=144). Recruitment ended once 20 providers agreed to participate. In order to best approximate providers likely to be treating 9/11 exposed persons and making referrals to 9/11 specialty care, recruitment parameters required a mix of practice types, provider specialties, and primary practice locations in lower Manhattan, upper Manhattan, the Bronx, Brooklyn, Queens, or Staten Island. Interested and eligible providers were then scheduled for a telephone interview; providers were offered \$200 as compensation for their time in the form of an honorarium or donation to the charity of their choice.

Semi-structured telephone interviews lasted approximately one hour. The interviewer's guide was developed by two of the authors (AEW and KC) and the vendor with input from representatives of the WTC Health Program clinics. Table 1 displays topics and sample questions from the guide. All 20 interviews were recorded and transcribed. The study was approved by the institutional review board of the NYC Department of Health and Mental Hygiene.

Qualitative analysis

The authors used thematic analysis [18] as the analytic framework to identify themes relevant to providers' knowledge and attitudes about 9/11-related health conditions and health care programs. Four of the authors (AEW, KC, JY, and LP) reviewed the transcripts and developed a list of 31 codes based on initial content review [18]. Next, the 20 transcripts were inductively open-coded [18-20] by two independent reviewers (JY and LP) using ATLAS.ti, version 6.0 (Scientific Software Development GmbH, Berlin, Germany). After the transcripts were coded, the original four authors met to review coded data and resolve discrepancies by mutual agreement.

Quantitative analysis

Providers were read a list of 12 health conditions and asked to rank the likelihood of an association between each condition and 9/11 exposure on a Likert scale of 1 (no likelihood) to 10 (very high likelihood). Providers were asked to rate how effective they thought each of five different forms of communication would be at

Table 2: Characteristics of providers interviewed (n=20).

| Current Practice Location | Practice Type | Years in Practice | Gender | Age Group | Practice Location on 9/11 |
|---------------------------|---------------------------------------------------------|-------------------|--------|-----------|---------------------------|
| Bronx | Gastroenterology | 25 | Male | 55-64 | Bronx |
| | Oncology | 29 | Male | 65-70 | Bronx |
| | Pediatrics | 2 | Female | 25-34 | N/A ^a |
| Brooklyn | Primary Care Provider ^b | 9 | Female | 35-44 | N/A ^a |
| | Pulmonology | 22 | Male | 45-54 | Brooklyn |
| Lower Manhattan (LM) | Allergy & Asthma | 19 | Male | 55-64 | LM |
| | Primary Care Provider ^b | 15 | Female | 55-64 | LM |
| | Primary Care Provider ^b | 6 | Female | 25-34 | N/A ^a |
| | Primary Care Provider ^b | 40 | Male | 65-70 | LM |
| | Primary Care Provider ^b | 20 | Male | 45-54 | LM |
| | Gastroenterology/PCP ^b | 22 | Male | 45-54 | LM |
| | Oncology | 11 | Female | 45-54 | LM |
| Queens | Family Practice | 18 | Male | 45-54 | Queens |
| | Neurology | 12 | Male | 35-44 | Queens |
| Upper Manhattan (UM) | Dermatology | 22 | Male | 45-54 | UM, Queens |
| | Neurology | 7 | Male | 35-44 | N/A ^a |
| | Ophthalmology/Surgical Oncology (Physician's Assistant) | 12 | Female | 35-44 | UM |
| | Podiatry | 15 | Male | 55-64 | LM, UM |
| | Psychology | 20 | Female | 45-54 | UM |

^aNot in practice on 09/11/2001

^bPrimary Care Provider (PCP) includes internal medicine and general practice

disseminating information about 9/11-related health programs and conditions on a Likert scale from 1 (not effective at all) to 10 (very effective). Mean and median scores were calculated for each health condition and form of communication; only providers that gave numeric responses were used to calculate the mean and median scores for each condition and form of communication.

Results

Provider characteristics

Background information about the providers interviewed is shown in Table 2. All of the providers were present in NYC on 9/11 and all but four were in practice in NYC at the time of the attacks. Sixty percent of the providers were male (n=12) and most (70%) were over age 45 years. The mean number of years in practice was 17, with the majority (n=13) in practice for 15 years or more. Most (n=13) providers were practicing in Manhattan at the time of the interview. More than half (n=13) have a specialty practice and the remainder are PCPs.

Thematic analysis

All 31 codes were reviewed to identify repeated patterns of meaning and categorized into one of five themes: 9/11-related health conditions and exposures, screening for 9/11 exposure and treatment, 9/11 program referrals, 9/11 program perceptions, and effective communication methods.

9/11-Related health conditions and exposures

Mean and median scores for the likelihood of association between

exposure to 9/11 and selected health conditions are listed in Table 3. Providers indicated their opinions were primarily based on their experiences with exposed patients.

I don't really know which ones are directly related. I think a lot of it is just sort of based on what I did see.

Providers were most likely to think that mental health conditions, such as depression, anxiety, or PTSD, were associated with 9/11 exposure (mean score = 9.1). Providers also felt there was a high likelihood of an association between 9/11 exposure and respiratory conditions including asthma/reactive airway dysfunction syndrome (RADS; 9.0), chronic sinus, nose and throat problems (7.9), and chronic obstructive pulmonary disease (COPD; 7.5).

...I had people who had no lung disease whatsoever now coming in with asthma and wheezing and with normal x-rays who now had abnormal x-rays.

Providers believed that cancer was commonly associated with 9/11 exposure (6.8); however, some providers feel it is difficult to establish a causal relationship between cancer and 9/11. Weaker relationships were perceived for cardiovascular disease (5.0), hypertension (4.6), gastroesophageal reflux disease (GERD; 4.2), auto-immune disorders (3.2), and diabetes (2.5). Although these conditions were considered less likely to have been directly caused by 9/11, physicians recognized that stress and environmental exposures resulting from 9/11 may have exacerbated these conditions or triggered their onset in predisposed individuals.

Table 3: Mean and median scores^a for 9/11-related health conditions.

| Condition | Mean | Median |
|----------------------------------------------------|------|--------|
| Mental Health Disorders | 9.1 | 10.0 |
| Asthma/Reactive Airway Dysfunction Syndrome (RADS) | 9.0 | 9.5 |
| Sinus/Nose/Throat | 7.9 | 8.0 |
| Chronic Obstructive Pulmonary Disease (COPD) | 7.5 | 7.5 |
| Cancer | 6.8 | 7.0 |
| Cardiovascular Disease | 5.0 | 4.5 |
| Musculoskeletal Disorders | 4.7 | 5.0 |
| Hypertension | 4.6 | 4.0 |
| Gastroesophageal Reflux Disorder (GERD) | 4.2 | 4.5 |
| Sleep Apnea | 3.9 | 3.0 |
| Auto-Immune Disorders | 3.2 | 3.0 |
| Diabetes | 2.5 | 2.0 |

^aMin = 0; Max = 10

Many providers felt that the current likelihood of association was impacted by degree of 9/11 exposure and the time between 9/11 and the onset of new symptoms and/or conditions. For example, some providers stated conditions with short latency periods developing more than 10 years post-9/11 were unlikely to be related.

I think you have to look at the temporal relationship between the onset of symptoms and the timing of the exposure, in order to make that connection.

The possibility of a connection between 9/11 and conditions with longer latency periods (e.g., cancer) was perceived to be stronger, although many providers indicated the need for additional data to more clearly identify such associations.

Screening for 9/11 exposure and treatment

Most providers considered 9/11 exposure an important part of patients' medical histories; however, few providers said they actually engaged in screening for 9/11 exposure or discussion about 9/11. Many providers indicated they learned about patients' 9/11 exposure through conversation or when patients introduced the topic. Several providers said that although not asked about specifically, 9/11 is often discussed during assessment of patients' occupational, environmental, and chemical exposures. Some providers did indicate that when patients come to them with symptoms or a condition without typical risk factor(s), they may be more likely to consider 9/11 exposure as a potential cause and possibly probe deeper about the extent of their exposure.

...as a part of my physical, I don't say to someone, "Were you exposed to 9/11?" unless there's some symptom that might make me think that it could be relevant.

Most providers did not feel 9/11 exposure is relevant at this point in time, in part, because many assumed most 9/11-related adverse outcomes have already been addressed. Several specialty providers said they did not screen patients for 9/11 exposure, because they believe it is unlikely that the conditions they treat are related to 9/11. While most providers did not experience challenges discussing 9/11-related issues or conditions with their patients, a few indicated they did not introduce the topic because they felt their patients may be reluctant to talk about their experiences.

Table 4: Mean and median scores^a for preferred communication methods.

| Communication Method | Mean | Median |
|------------------------------------|------|--------|
| Continuing Medical Education (CME) | 7.2 | 7.5 |
| In-Services | 7.2 | 7.3 |
| Physician Detailing | 7.0 | 7.0 |
| General Education Materials | 6.3 | 6.3 |
| Grand Rounds | 5.9 | 7.0 |

^aMin = 0; Max = 10

When asked, the majority of providers stated that their evaluation and treatment plans would not differ if they thought a patient's condition was related to 9/11. For example, most providers did not believe that asthma caused by 9/11 exposure should be treated differently than asthma triggered by another cause. Despite the lack of screening, several providers indicated that if they knew patients had 9/11 exposure, they would refer them to a 9/11 health program.

9/11 Program referrals

A number of providers interviewed stated that they had referred patients to a 9/11 program for a physical or mental health condition that may be related to 9/11. Providers did not identify the WTCHP by name, but mentioned specific clinic locations. Providers were most aware of and most commonly referred patients to the 9/11 programs at Mount Sinai Hospital (responder program) and Bellevue Hospital (survivor program), as they believed these institutions have great reputations.

Bellevue is known worldwide for its psychiatric services, long before 9/11. It's been the premier facility for treating psychiatric disorders and that's the number one place I would tell people.

Providers also indicated they referred patients to the responder program at University of Medicine and Dentistry of New Jersey (currently Rutgers University) and North Shore Long Island Jewish, and the survivor program at Elmhurst Hospital, although these programs were generally less well known. A few providers cited ongoing research studies at 9/11 programs as a reason for their referral. Once referrals were made, the providers interviewed reported positive experiences, as patients were satisfied with the services provided by 9/11 specialty providers. Providers also referred patients to outside specialists not associated with 9/11 programs including area psychologists, psychiatrists, and pulmonologists.

Providers also described reasons they had not referred patients to available 9/11 programs, including the fact that some patients had self-referred to 9/11 specialty care. A few providers cited lack of knowledge of 9/11 programs as a reason for not referring exposed patients. A small number of providers indicated they did not refer patients to a 9/11 program because they were concerned that the programs were focused more on research than treatment. When prompted, all providers stated they would refer patients to 9/11 specialty care and most were not concerned about patients leaving their practice.

Most providers believed that responders with long or high levels of exposure to 9/11 ought to be referred to the WTC Health Program for evaluation. When informed of annual monitoring services for eligible 9/11 responders, providers indicated they would refer even

if their patients were currently healthy, as some health conditions associated with 9/11 may develop later or emerge over time.

If they have exposure and they have no symptoms, symptoms unfortunately can be much later on, delayed, particularly when you're talking about cancer and other things that may take decades to develop.

9/11 Program perceptions

The majority had positive comments about the 9/11 programs and/or the utility of 9/11-related services in general. Many comments were based on providers' experiences with the programs directly or through feedback from their patients. Generally, providers felt the programs provided "wonderful" service. Care at the programs was described as sympathetic and compassionate and dedicated to the persons with the greatest risk of developing 9/11-related health problems. Providers who referred patients were pleased with the services their patients received and more importantly, believed that their patients were happy with services they received. Several providers felt that the main draw of the 9/11 programs was their institutional knowledge base, including their experience prior to 9/11 as environmental and occupational health centers and the cumulative knowledge gleaned from having treated thousands of persons exposed to 9/11. The availability of care at no out-of-pocket cost at the WTC Health Program was another advantage cited by providers.

Providers were impressed by the multidisciplinary approach employed at the programs, which enables patients to receive integrated physical and mental health care. Providers believed that one of the greatest benefits was the potential to monitor patients over the long-term, as many conditions resulting from environmental and toxic exposures have long latency periods. Providers believed that 9/11 monitoring is important on an individual level and for public health knowledge in general.

...it's a very well thought out collaboration between medical specialists, nursing, psychologists, nutritionists, all kinds of modalities available to them at no costs. That's the way it should be.

...the necessity, I think, is clear...after-effects of environmental exposures don't necessarily present soon thereafter...

Only a small number of providers had negative comments about the 9/11 programs and were concerned about the convenience of program locations and how the program could be accessed by persons living outside NYC. Some providers were concerned that program use may lead to a lack of coordination of care resulting in individuals seeing multiple providers for the same condition or replacing their PCP with a specialist. Other negative perceptions included concerns about the depth of specialties in the network, the level of provider expertise, how providers are assigned to patients (e.g., mental health clinicians), and appointment wait times.

Effective communication methods

Sources used to obtain information on 9/11-related conditions included the internet (search engines, government and health websites), and medical journals. Throughout the interviews, providers expressed interest in receiving research findings from various 9/11 health studies, suggesting these would be useful tools for diagnosis and treatment of their patients.

...I think it probably would be a good idea if, in a very simplified

manner...they have some kind of educational thing. Not only for patients, but for doctors saying, here's the research results we have from screening the fire fighters and police and other people who had high exposure during 9/11.

At the conclusion of the interviews, providers were asked about the best way to provide them with current information on the 9/11 programs and related conditions. Most providers expressed interest in receiving educational tools and information on 9/11-related research and medical conditions.

...I feel like a lot of information is sitting at the academic centers... but I think there's a lot of local area medical professionals, not just physicians, that would benefit from having access to information to improve the quality of their care. Specifically since so many of us are caring for people that either worked directly in the WTC or in the area surrounding it.

They described methods to effectively disseminate such information to the general provider community, including in-person representatives (e.g., physician detailing), continuing medical education (CME), lectures, and printed and electronic materials. Many providers indicated that information received from in-person representatives (e.g., physician detailing (mean score = 7.0) and in-services at group practices (7.2)) is direct, informative, and convenient. Conversely, other providers expressed concerns about time constraints as barriers to receiving information in-person.

Some providers suggested that incorporating 9/11 information into CME activities (7.2) could best reach the provider community. Other providers suggested general educational materials (6.3) including advertisements in medical journals, direct mailings, and emails as effective ways of disseminating information to providers. A few providers also mentioned lectures at grand rounds (5.9), professional workshops, and conferences as effective ways to provide information.

Providers suggested disseminating patient-centered health education materials to assist 9/11-exposed patients in discussing and coordinating medical care with their providers, including symptom checklists, information on 9/11-related illnesses, and specialty treatment centers and clinics.

I think they [sic patients] should be provided with evidence that deals with the illnesses which are pretty strongly tied to 9/11 exposure, i.e., lung disorders, emotional disorders, and cancer...they should be given a balanced approach to deal with it and what they can expect, and be provided with sources of treatment, places they can go to address these issues.

Discussion

In this study, we gained a better understanding of providers' knowledge of 9/11-related medical conditions, opinions of and inclination to refer patients to the 9/11 treatment programs, and the preferred methods to provide them with information about conditions and programs.

When providers were asked about the potential association between 9/11 and specific health conditions, for many, the tendency was to answer in terms of their actual experiences treating 9/11-exposed patients and not to respond if they hadn't seen patients

with these conditions. Most were hesitant to answer the question when it referred to a condition outside their practice area or with which they had little experience. Providers agreed that assessing the association between 9/11 and a patient's medical condition was largely dependent upon the time between 9/11 and the onset of symptoms, as well as the condition's latency period.

In both the media and scientific literature, mental health, respiratory illness, and GERD are the conditions most commonly associated with 9/11. The above conditions, along with over 50 types of cancer, represent the majority of conditions for which treatment is covered at the 9/11 programs, which is likely why the associations between 9/11 and these conditions were ranked highest by providers. There is an emerging body of scientific evidence that links other conditions such as cardiovascular disease, sleep apnea, and diabetes with 9/11-related exposures and PTSD; however, few providers were aware of this research and subsequently, the potential relationship between these conditions and 9/11 exposure. This lack of information appeared to influence physician referrals to the 9/11 programs and is important to address.

Interestingly, although most providers said that exposure to 9/11 is an important piece of one's medical history, they did not routinely screen for exposure to 9/11. It is possible providers said it was important because they were being interviewed about 9/11-related health and they wanted to give the desired response, but when probed further, revealed that 9/11 exposure was not a major factor in patient assessment and treatment. Providers indicated that knowing a patient's health condition was related to 9/11 exposure would not affect their treatment plan, thereby reducing the importance of screening for exposure. Providers were apt to discuss their opinions on diagnosing new conditions more than 10 years after 9/11, but did not discuss the potential effect of 9/11 on previously diagnosed chronic conditions (e.g., asthma, diabetes, PTSD, depression, etc.) in either new or current patients. In many cases, having a medical condition caused by 9/11 exposure may not necessitate a different course of treatment; however, there is preliminary research indicating that some respiratory conditions observed in 9/11-exposed patients may manifest differently than in non-exposed persons [21].

In general, providers spoke highly of the programs and understood that the knowledge gleaned from treating 9/11-exposed persons collectively was invaluable. Conversely, several providers were concerned that the programs were too focused on research at the expense of patient care. Providers were familiar with the programs at Mt. Sinai and Bellevue Hospitals, although most did not know there was a distinction between the two arms of the program, which affects eligibility and at which locations persons receive care. Although providers knew treatment at these programs was available at no out-of-pocket cost, when it came to discussing specific details about the programs such as eligibility, covered conditions and services, provider expertise, program locations, monitoring visits, etc., several providers gave incorrect information. This lack of knowledge regarding specific details about the programs is a crucial area for the WTCHP to address through outreach and education. Without correct information, providers may not refer patients to the correct program, may refer patients who are not eligible, and may not provide accurate instructions as to how to apply for the WTCHP.

As such, patients may become frustrated and ultimately, not follow through with the referral. Moreover, specific information about the balance between research and treatment, expertise of the providers, numerous clinic locations, and wide range of conditions covered and services provided are crucial elements to increase the likelihood that providers make a referral to the WTCHP and to encourage the patient to accept the referral.

Almost all providers expressed interest in learning more about the 9/11 programs and 9/11-related conditions, specifically indicating that summaries of the scientific literature on 9/11 health would be informative in providing care to 9/11-exposed patients. It is evident from the interviews that it is necessary to get this information to providers, as knowledge gaps existed with respect to the association between medical conditions and exposure, as well as specific details about the WTCHP (e.g., eligibility requirements, application process, etc.). The difficulty lies in disseminating information to providers, as there does not appear to be a one-size-fits-all approach. In-person visits, to individual providers or small group practices, which received favorable reviews, are likely to be labor intensive and costly. Although 9/11 research is typically published in a variety of journals, many are specialty-focused and may not be read by a broad range of providers. For example, information on the restrictive patterns of lung function seen in WTC-exposed patients with persistent respiratory symptoms and unexplained reduction in vital capacity [21] and the long-term nature of many of the conditions associated with 9/11 (e.g., asthma, PTSD, depression, etc.) may be useful for providers treating such patients, but are published in specialty journals. As such, summaries of the literature that are readily accessible could prove extremely useful to NYC-based providers. Based on suggestions from providers, these summaries could be disseminated as CME activities, direct mailings, or other general educational materials.

A few providers expressed concerns that patients receiving care from a 9/11 program may ultimately experience a lack of coordination of care, see multiple providers for the same condition, or leave their PCP. However, care at the 9/11 programs is designed to be carefully coordinated among both providers within and outside the program. Program physicians are encouraged to work with patients' current providers to ensure they are receiving optimal care with the added benefit of services at the 9/11 program being available at no cost for covered conditions. Moreover, it is important for providers to encourage their patients to continue receiving monitoring and treatment at the 9/11 programs once enrolled, as appropriate.

Although we included a broad range of provider types and practice locations, a limitation of this study is that the 20 providers selected for this study are not necessarily representative of all providers in NYC. However, interviewing these selected providers allowed us to glean information about provider knowledge regarding 9/11 health issues, as well as insights into WTC program awareness and referral patterns.

Conclusion

This study helped provide insight as to what NYC-based providers believe about 9/11-related medical conditions and treatment programs. Given that many patients are more likely to see a specialist when the referral is made or endorsed by their PCP, they are an important factor for exposed persons seeking care at a 9/11 program.

These findings may be useful to administrators of the WTC Health Program, in particular those overseeing the program's outreach and education planning. The WTCHP is encouraged to include NYC-based providers in future education and outreach campaigns, in order to increase their likelihood of making referrals. Providers should be furnished with materials that provide detailed information on program locations, eligibility requirements, services and advantages, summaries of 9/11 research on known and emerging conditions related to 9/11, and patient educational materials. Most importantly, it is key to remind both providers and exposed persons that every patient seen at a 9/11 program, healthy or sick, for monitoring or for treatment, makes a contribution to the body of knowledge on 9/11 health.

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