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Title: A qualitative examination of health and health care utilization after the September 11th terror attacks among World Trade Center Health Registry enrollees
Committee: Environmental Health Sub-Committee
Topic: Disaster epidemiology: tools, data, experiences, and challenges
Keywords: Disasters|Health care|Special populations

Background:

The World Trade Center (WTC) Health Registry (Registry) is a cohort study of long-term physical and mental health outcomes in 71,437 survivors of the terrorist attacks of September 11, 2001. Registry follow-up data gathered in 2006-07 showed a high prevalence (19.5%) of 9/11-related probable posttraumatic stress disorder as well as numerous reports of continuing 9/11-related respiratory and reflux symptoms. Registry data also indicate that at least one-fourth of individuals with 9/11-related symptoms and illnesses did not use 9/11-related health care services, despite extensive education and outreach efforts. Since 2009, the Registry's Treatment Referral Program (TRP) has encouraged enrollees and others with 9/11-related physical or mental health conditions to seek 9/11 specialty care. We sought to improve the quality of the program through a better understanding of low health care utilization by enrollees and barriers to service utilization.

Methods:

Six focus groups were conducted in January 2010 with diverse subgroups of enrollees, who were likely eligible for 9/11-related treatment services. The 48 participants were of differing race/ethnicities, ages, and boroughs of residence. Qualitative analysis of focus group transcripts was conducted using open coding and the identification of recurring themes.

Results:

Participants described a variety of physical and mental health symptoms and conditions, yet their knowledge and utilization of 9/11 healthcare services were low. Participants highlighted numerous barriers to accessing 9/11 services, including programmatic barriers (lack of program visibility and accessibility), personal barriers such as stigmatization and unfamiliarity with 9/11-related health problems and services, and a lack of referrals from their primary care providers. Many participants were reluctant to connect their symptoms to the events of 9/11 due to lack of knowledge, the amount of time that had elapsed since 9/11, and the attribution of current health symptoms to the aging process.

Conclusions:

Knowledge of barriers to 9/11-related health care has led to improvements in the Registry's ability to refer eligible enrollees to appropriate treatment programs. For example, the Registry has placed additional emphasis on specialized training of staff to enhance motivational interviewing skills to better educate enrollees on the possible connection between their symptoms and the 9/11 disaster and minimize feelings of apprehension about the connection, and has conducted outreach to area medical providers. Moreover, these findings highlight areas for consideration in the implementation of the new federal WTC Health Program, now funded under the James Zadroga 9/11 Health and Compensation Act (H.R.847), which includes provisions for outreach and education.

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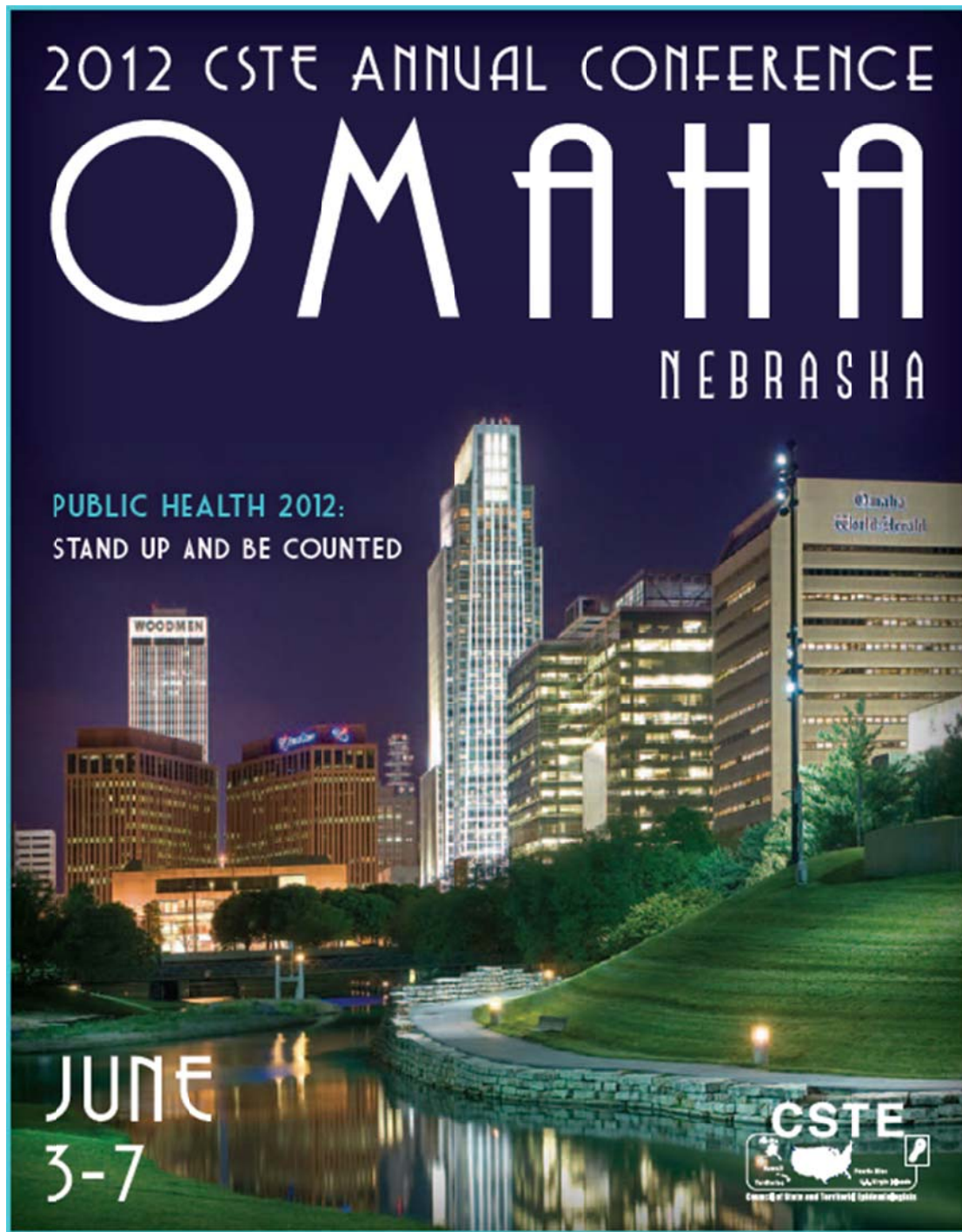
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