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Evaluating Ascertainment of Hepatitis C Cases and Deaths by Electronically Linking Surveillance and Vital Statistics Data in Utah

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Objective

To evaluate the ascertainment of deaths among hepatitis C virus (HCV)-infected persons reported to public health and to identify additional HCV cases not reported to public health in Utah through review of death certificate data.

Introduction

While HCV infections are associated with substantial morbidity and mortality in the United States, deaths due to HCV may not be detected well in Utah's surveillance system. New interferon-free drugs for HCV can result in virologic cure with limited side effects, but treatment is expensive. It will therefore be increasingly important that public health accurately document the prevalence of HCV and outcomes, such as death, to inform policy makers and others who are responsible for allocating resources. A previous analysis conducted in Utah determined that a two-step methodology electronically linking death certificate data to HIV surveillance data was effective at ascertaining previously unreported deaths and cases in the HIV-infected population.[1] Similarly, linkage to death certificate records may also provide an important avenue to identify deaths among the chronic HCV cases included in surveillance data and identify cases of HCV not previously reported to public health in Utah.

Methods

A spreadsheet of all chronic HCV infections with investigations initiated by the Utah Department of Health from was generated using Trisano®, Utah's electronic surveillance system. Electronic death certificate data were obtained from Utah Vital Statistics for 2009-2012. Electronic record linkage was utilized to match surveillance and death certificate data using first and last name, gender, and date of birth. A subsequent manual search of death certificate records was conducted to identify persons with an underlying or contributing cause of death attributed to chronic HCV infection (ICD-10 code B182). Persons with causes of death including HCV infection who had not previously been reported to public health were identified. Date of birth was determined for all persons who had died of HCV during the time frame and were identified in this study.

Results

Overall, 600 deaths among HCV-infected individuals were identified between 2009 and 2012 in Utah. Using electronic record linking, 346 deaths among persons with chronic HCV infection were identified. Of these, only 34 (9.8%) deaths had been reported to public health. Manual search of death certificate records identified 350 individuals with HCV-associated underlying or contributing codes. Among these, the proportion previously documented in Trisano® as HCV cases and as deceased HCV cases was 27% (n=96) and 6% (n=21), respectively. Seventy-three percent (254/350) of individuals with death certificate codes associated with HCV were newly identified as cases not previously reported to the public health. The majority (76%) of deaths in this study occurred in persons born between 1945-1965.

Conclusions

The results of this analysis suggest that death certificate record linkage may provide a mechanism to more accurately measure the prevalence of people living with chronic conditions, such as HCV infection, in Utah. Despite this fact, the majority of deaths due to HCV infection in Utah were in persons who had never previously been reported to public health. These data support the need for extended HCV testing in Utah, particularly for those with risk factors or within the age cohort born 1945-1965 population. Additionally, they support the creation of a hepatitis C registry in Utah in order to gain better understanding of the infected population and support interventions to prevent the morbidity and mortality associated with the disease.

Keywords

Data linkage; Communicable diseases surveillance; Death ascertainment; Hepatitis C virus

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References

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