

Collecting Sexual Orientation and Gender Identity Data in Suicide and Other Violent Deaths: A Step Towards Identifying and Addressing LGBT Mortality Disparities

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Abstract

Sexual orientation and gender identity (SO/GI) are not systematically recorded at time of death, limiting identification of mortality disparities in lesbian, gay, bisexual, and transgender (LGBT) people. LGBT populations are thought to have elevated risk of suicide based on high rates of reported lifetime suicide attempts. Lack of data on suicide deaths, however, hinders understanding of the prevalence and patterns of suicide among LGBT populations and development of targeted interventions and prevention programs. This report describes recent efforts to address this knowledge gap by systematically collecting SO/GI information in the investigation of suicide and other violent deaths.

Key words: gender identity, health disparities, LGBT mortality, mortality disparities, postmortem data collection, sexual orientation, suicide, violent death.

Introduction

IN THE UNITED STATES, decedents are routinely and systematically identified by such characteristics as age, sex, marital status, service in United States Armed Forces, education, race/ethnicity, and occupation. Sexual orientation and gender identity (SO/GI), however, are not similarly recorded. Lack of data on SO/GI obscures causes of death among lesbian, gay, bisexual, and transgender (LGBT) people, hindering attempts to identify and address mortality disparities affecting these populations.

Despite considerable evidence that LGBT people attempt suicide at significantly higher rates than the general population, not knowing whether LGBT people are more likely than others to die by suicide has long limited efforts to understand and prevent these deaths. This report describes recent efforts to begin addressing this knowledge gap by collecting SO/GI information in the investigation of suicide and other violent deaths.

Background

In 2012, a task force of the National Action Alliance for Suicide Prevention composed of LGBT researchers, health

professionals, public sector employees, and community representatives, successfully advocated for inclusion of LGBT populations among *groups with increased suicide risk* in the revised National Strategy for Suicide Prevention.¹ This designation was supported by more than four decades of research pointing to elevated suicidal ideation and suicide groups with increased attempts in LGBT people. A meta-analysis of data from 25 international studies found gay and bisexual men were four times more likely to report lifetime suicide attempts than heterosexual men, and lesbian and bisexual women were twice as likely as heterosexual females.² A meta-analysis of 19 adolescent studies found LGB youth reported lifetime suicide attempts at three times the rate of heterosexual youth, and were four times more likely to report medically serious attempts.³ Many different surveys of transgender respondents have found lifetime attempts reported by 25–43%,⁴ compared to less than 5% of American adults overall.⁵

In the population as a whole, non-fatal suicide attempt is a salient risk factor for suicide death. Seventy percent of attempters make no further attempts,⁶ however, and a small percentage of those making even serious attempts (estimated at 13%) die by suicide in the next several

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decades.⁷ Further, demographics of suicide attempters differ from those who complete suicide. Females attempt suicide more frequently than males but account for only 21% of all suicide deaths. Persons aged 15 to 24 make far more non-fatal suicide attempts than those aged 70 and over but have a suicide rate of 11 per 100,000, compared to 16 per 100,000 among older adults. Thus, high rates of suicide death among LGBT populations cannot be assumed from elevated reports of non-fatal suicide attempts.

Studies have produced inconsistent findings about whether LGBT people die by suicide at higher rates than heterosexuals. Three psychological autopsy studies concluded that homosexuals were not over-represented in consecutive samples of adolescent and young adult suicide decedents,⁸⁻¹⁰ although this finding has been challenged based on small numbers and other methodological limitations.¹¹ An analysis of Danish data found that men in same-sex registered partnerships (which may serve as a proxy of gay or bisexual identity) were eight times more likely to die by suicide than men who were married to women and twice as likely as never-married heterosexual men, although no differences were observed among comparable female groups.¹² Follow-up of a U.S. survey sample of men reporting same-sex sexual partners found no evidence of higher suicide risk,¹³ but follow-up of a sample from a national survey of men and women found an elevated rate of suicide among participants reporting same-sex sexual partners who lived in communities high in anti-gay prejudice.¹⁴ European clinical studies have identified disproportionate numbers of suicide deaths in individuals receiving medical interventions for gender transition.^{15,16} A recent Australian study identified just one percent of decedents in a state suicide registry as LGBT, based on anecdotal data.¹⁷ LGBT decedents, however, appeared to constitute a unique subset of suicide decedents, with more depression, relationship problems, and other life stressors; absence of psychotic disorders; and lower rate of psychiatric treatment.

This accumulated literature suggests the limitations of studies using inconsistent samples and methodologies to produce definitive information about the prevalence and patterns of suicide in LGBT populations. Standard mortality statistics have proven invaluable in identifying suicide disparities between men and women, and among groups defined by age, race/ethnicity and other demographic characteristics. Similarly, answering the question of whether sexual and gender minorities have higher rates of suicide than majority populations do requires routine, systematic identification of SO/GI at the time of death.

Expert Convening

To begin addressing this critical topic, in May 2014, the American Foundation for Suicide Prevention (AFSP) and the Johnson Family Foundation (JFF) convened a two-day meeting of suicide researchers, epidemiologists, LGBT experts, and representatives of agencies and organizations having responsibility for collecting and/or disseminating mortality data. In addition to AFSP and JFF, participants' affiliations included the National Action Alliance for Suicide Prevention, Centers for Disease Control and Prevention, National Violent Death Reporting System, National Association of Medical Examiners, American Board of Medicolegal Death Investigators, National Association for Public Health Statistics and

Information Systems, Williams Institute at UCLA School of Law, and the Department of Veterans Affairs. Also represented was the Conference of Chief Coroners and Chief Medical Examiners of Canada, which is collaborating with a national LGBT organization to develop an investigative protocol to identify SO/GI in youth suicide decedents.

The aims of the convening were to discuss the potential and limitations of current federal and state postmortem data collection procedures to accurately identify and record SO/GI in suicide decedents; identify supplementary or alternative procedures; and begin planning a pilot study in which a promising approach could be tested through voluntary implementation in a limited number of jurisdictions. Summarized below is the consensus of participants that emerged through discussions at the convening and in our ongoing collaboration as the Working Group for Postmortem Identification of SO/GI.

Death Certificates

Early in the convening, participants discussed the appropriateness of the U.S. Standard Certificate of Death for collecting SO/GI data. Several factors led to a consensus against what might appear *prima facie* to be a simple, direct and universal way of eliciting this information: First, as a practical matter, revising the federal death certificate to add SO/GI items is unlikely in the near future. The Centers for Disease Control and Prevention (CDC) last revised the death certificate in 2003, following an extensive evaluation process, and that form is as yet not used in all states. Another revision is not currently being considered. Second, the death certificate assigns responsibility to the funeral director to complete items on the decedent's demographic characteristics. If SO/GI items were added, funeral directors may not be motivated or well equipped to elicit this information from the next of kin or other informant. If the informant does not know or wish to provide the information, funeral directors are unlikely to pursue the matter with others. Third, because the death certificate is generally public information and used by survivors for many instrumental purposes, privacy concerns may be heightened.

California has recently amended existing law to require that the person completing the death certificate record the decedent's sex to reflect current gender identity, as reported by the informant or as identified in specified legal documents or medical records.¹⁸ While this provision significantly advances respect for transgender people after death, it does not identify the decedent as transgender and thus does not facilitate identification of causes or circumstances of death that may be disproportionately high among transgender people.

Alternative Protocol

Most of the subsequent discussion among convening participants focused on an alternative protocol for collecting and reporting decedents' SO/GI.

Scope

Although the primary focus of the convening was on suicide, the scope of the protocol was expanded to include all deaths included in the National Violent Death Reporting System (NVDRS) since this was considered the ideal mechanism

for aggregating, coding, and reporting SO/GI data collected by individual jurisdictions. NVDRS is a state-based surveillance system, introduced by CDC in 2002 to enhance understanding of violent deaths, guide prevention efforts, and track progress over time.¹⁹ Pooling information from multiple sources including death certificates, crime labs, and medical examiner, coroner and law enforcement reports, NVDRS maintains an anonymous, publicly accessible database on deaths from suicide, homicide, unintentional firearm injuries, law enforcement actions, and undetermined intent. NVDRS is currently implemented in 32 states and will ultimately expand to include all states, establishing a national database on violent deaths.

Responsibility for collecting SO/GI data

Because all NVDRS-defined deaths are subject to medicolegal investigation, on-scene death investigators were considered best positioned to determine decedents' SO/GI. Death investigators are trained to elicit sensitive, sometimes conflicting information from a variety of informants, and current death investigation guidelines identify decedents' sexual history as a relevant topic.²⁰ However, no specifics are provided about what should be included under this topic, and SO/GI information is not presently collected in any systematic way. A key task of our future work is to develop appropriate guidelines, procedures, and data collection instruments to facilitate death investigators' accurate identification of SO/GI in all violent deaths. A multi-method approach will be utilized, combining observation of "clues" at the scene and in the decedent's environment, informal conversations with informants, and structured questions that adapt best practices for SO/GI measurement to the postmortem setting.^{21,22} Wherever possible, information on SO/GI will be sought from multiple informants.

Reporting

The death investigator's report will identify the decedent's SO/GI and summarize supporting evidence. This will be incorporated into the medical examiner or coroner's report, along with any additional supporting evidence from medical certification of the death.

Coding of SO/GI information

The NVDRS database includes over 200 data elements about the decedent and the death. Beginning with 2014 deaths, several data items have been amended or added to capture SO/GI information, although currently this information is likely to be anecdotal or absent from many death records. In addition to establishing systematic procedures for collecting SO/GI data in the death investigation, our group will help facilitate consistency between data collection and coding formats for SO/GI variables, thus enhancing the accuracy of SO/GI identification in the NVDRS database.

Pilot testing of protocol

Following full development and in-depth training of death investigators and other relevant personnel, the protocol will be voluntarily implemented and evaluated in several jurisdictions.

Challenges and Constraints

In the proposed protocol, valid identification of decedents' SO/GI relies essentially on informants' knowledge and will-

ingness to share this information with death investigators. Although death investigators' reliance on multiple informants will increase validity, SO/GI-related stigma poses a challenge that may be difficult to overcome in some areas of the country.

Reliance upon NVDRS to aggregate and report SO/GI data also presents challenges. Full implementation across the U.S. is still several years away. Also, rather than collecting information firsthand, NVDRS examines and codes existing death records and reports obtained from multiple local sources, including medical examiners, coroners and law enforcement offices. The content and quality of the information varies by jurisdiction and among different units in the same jurisdiction, and although considerable effort is invested in developing standard codes for variables of interest and training local personnel in their use, the interpretation of information may not be consistent across the system.

In addition, even if lesbian, gay, bisexual, and transgender people are accurately identified through the new death investigation protocol and accurately reported through NVDRS, better methods of determining the prevalence of each of these populations in comparable geographic jurisdictions must be developed in order to determine rates of deaths due to suicide, homicide, and other violent means for LGBT people. Finally, the proposed work will focus only on violent deaths. The large majority of LGBT people, like most of the general population, die from other than violent causes, and procedures for identifying SO/GI in these decedents will still need to be developed and tested.

Notwithstanding these constraints, we believe this work represents a significant step toward the goal of routinely and systematically identifying SO/GI at the time of death. We look forward to working with others to further expand the scope of our protocol and encourage additional ways to collect postmortem data on these critical variables.

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Author Disclosure Statement

No competing financial interests exist.

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