Improving National Data Systems for Surveillance of Suicide-related Events

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Abstract

Background—Describing the characteristics and patterns of suicidal behavior is an essential component in developing successful prevention efforts. The Data and Surveillance Task Force (DSTF) of the National Action Alliance for Suicide Prevention was charged with making recommendations for improving national data systems for public health surveillance of suicide-related problems, including suicidal thoughts, suicide attempts and deaths due to suicide. Data from the national systems can be used to draw attention to the magnitude of the problem and are useful for establishing national health priorities. National data can also be used to examine differences in rates across groups (e.g., sex, racial/ethnic, and age groups) and geographic regions, and are useful in identifying patterns in the mechanism of suicide, including those that rarely occur.

Methods—Using evaluation criteria from the Centers for Disease Control and Prevention, the World Health Organization, and the U.S.-based Safe States Alliance, the DSTF reviewed 28 national data systems for feasibility of use in the surveillance of suicidal behavior, including deaths, non-fatal attempts and suicidal thoughts. The review criteria included such attributes as the aspects of the suicide-related spectrum (e.g., thoughts, attempts, deaths) covered by the system, how the data are collected (e.g., census, sample, survey, administrative data files, self-report, reporting by care providers), and the strengths and limitations of the survey or data system.

Results—The DSTF identified common strengths and challenges among the data systems based on the underlying data source (e.g., death records, health care provider records, population-based surveys, health insurance claims). From these findings, the DSTF proposed several recommendations for improving existing data systems, such as using standard language and definitions, adding new variables to existing surveys, expanding the geographic scope of surveys to include areas where data are not currently collected, oversampling of underrepresented groups, and improving the completeness and quality of information on death certificates.

Conclusions—Some of the DSTF recommendations are potentially achievable in the short term (<1–3 years) within existing data systems, while others involve more extensive changes and will require longer term efforts (4–10 years). Implementing these recommendations would assist in the development of a national coordinated program of fatal and nonfatal suicide surveillance to facilitate evidence-based action to reduce the incidence of suicide and suicidal behavior in all populations.

Introduction

Data and surveillance form the foundation for the public health model of prevention (1). They are essential for describing the public health issue, identifying risk and protective factors for adverse health conditions, and evaluating interventions (2). Public health surveillance has been defined by Centers for Disease Control and Prevention (CDC) as "the ongoing, systematic collection, analysis, interpretation, and dissemination of data about a health-related event for use in public health action to reduce morbidity and to improve health" (3).

The public health model of prevention includes four basic steps: 1) define and monitor the problem; 2) identify risk and protective factors; 3) develop and test prevention strategies; and 4) assure widespread adoption of effective prevention programs (1). To apply the public health model to suicide prevention, data systems to monitor the problem must be available. However, monitoring suicidal behavior and outcomes at a national level can be challenging for several reasons including:

- There is a lack of clarity on what exactly should be monitored (4). Should we monitor all self-directed violence (an all-encompassing term for a range of violent actions), suicides, nonfatal suicidal behavior (i.e., suicide attempts), non-suicidal self-harm (e.g., behaviors such as self-mutilation), suicidal thoughts, or some combination of these?

- Most of the data systems currently used to estimate trends in suicidal behavior were not designed solely to address this subject (5). In these data systems, questions specific to suicide are often limited and the data collected rarely provide the depth of information desired to inform effective prevention and intervention efforts. For example, some systems (e.g., hospital emergency department records) are designed to collect data on multiple health conditions, not just visits related to suicide. Altering these systems to enhance their capacity to collect suicide-related information may be difficult (6).

- Data on suicides can be problematic for several reasons, including: geographical differences in death investigation methods and how equivocal cases are classified; lack of funding for coroner's or medical examiner's offices to conduct comprehensive investigations on all appropriate incidents; and differences in the extent to which potential suicides are investigated to accurately determine the cause of death (7, 8).

- In addition, timeliness of national estimates of suicides can be hindered due to the complexity of the death certification and registration process. The investigative and reporting processes at the state level often involve multiple parties, including vital registrars, medical examiners, coroners, physicians, toxicology laboratories, hospitals, nursing homes, and hospices. Data from the states must be aggregated at a national level in order to obtain national numbers that are complete and accurate. Because of the number of steps and processes involved, there is currently about a one year delay in determining the preliminary national suicide rate and a nearly two year delay for the final rate, making it difficult to implement timely adjustments to suicide prevention efforts or redirection of prevention resources (7).

As one of the many task forces created through the National Action Alliance for Suicide Prevention (NAASP), the Data and Surveillance Task Force (DSTF) was established to help improve and expand the information available about suicide and suicidal behavior. The DSTF was charged with making recommendations for improving national data systems for suicide surveillance, particularly with regard to enhancing or expanding existing systems

and improving the quality, timeliness, usefulness, and accessibility of data on suicide and suicidal behavior. The DSTF reviewed the characteristics of existing data systems to identify their current usefulness in monitoring suicide and suicidal behavior and to identify gaps and areas for improvement. This report summarizes the findings from the review; discusses strengths and weaknesses related to data on suicide in the major types of data sources available; and provides recommendations for improving data timeliness, quality, and accessibility.

Methods

The DSTF focused the review on data systems that had the potential to provide national estimates on three aspects of self-harm: suicidal thoughts, nonfatal suicide behavior (i.e., suicide attempts) and suicide deaths. While several surveillance systems were identified that collect data on entire communities (e.g., the White Mountain Apache Tribally Mandated Suicide Surveillance System (9)) or selected metropolitan areas, states or regions (e.g., National Addictions Vigilance Intervention and Prevention Program (NAVIPPRO™) (10), Researched Abuse, Diversion and Addiction-Related Surveillance (RADARS®) System (11)), these non-national systems were not reviewed. Data systems included in the review were operational as of November 2011.

The Task Force used existing guidelines (12-14) to focus the review process. Attributes considered included:

- The aspects of the suicide-related spectrum (e.g., thoughts, attempts, deaths) covered by the system

- The segment of the population (e.g., youth, adults, military/veterans, incarcerated individuals) included in the system

- How the data are collected (e.g., census, sample, survey, administrative data files, self-report, reporting by care providers)

- How often the data are collected (e.g., ongoing, annually, periodically)

- The length of time before data are available for analysis and use

- Whether the quality of the data (e.g., response rates, reliability, validity, completeness) has been assessed

- How the data have been used

- The strengths/limitations of the survey or data system

- Whether and how the data system could be modified to improve the information on suicide events (e.g., expand to other populations, include additional questions, expand coverage to more states)

Reviews were based on information provided on websites or from briefings made to the task force by individuals knowledgeable about the data system. The observations and conclusions made by the task force were not reviewed or confirmed by the agencies or organizations that operate the systems.

Results

A complete list of the data systems reviewed is provided in Table 1.The DSTF identified many common characteristics in the strengths and challenges of different systems based on the underlying type of data involved (e.g., population based surveys, health care records). These generalized observations are summarized in Table 2. For example while death certificate data are often captured from an in-depth investigation of the suicide, the information recorded on a death certificate might be limited and some demographic factors (e.g., race/ethnicity, veteran status) could potentially be misclassified because information is collected from next-of-kin or friends of the deceased. Health provider records often provide more detailed data about the individual involved, but the data might not include all members of a population so it often difficult to calculate rates or determine prevalence. Population-based surveys are usually timely and flexible but can be expensive to administer and usually rely on self-report.

Conclusion

The findings from the review of systems were used to develop recommendations submitted to the NAASP. These recommendations are summarized below.

- Use standard language and definitions on self-harm and suicidal thoughts and behavior in coding manuals and national surveys.

  - Public and private organizations should adopt and promote the use of standard definitions such as those described in the CDC's *Self-Directed Violence Surveillance Uniform Definitions and Recommended Data Elements* (4) and the Department of Veterans Affairs' Self-Directed Violence Classification System (15).

- Add missing key variables or data elements (e.g., socio-demographics, mechanism of injury) to existing nonfatal data systems to enhance their usefulness for suicide-related surveillance. Some surveillance recommendation documents contain lists of data elements that could be considered (4, 13-15).

  - Add suicidal thought and behavior questions to the core items of national behavioral risk factor surveys on general health (16).

  - Include valid and reliable questions regarding sexual orientation/gender identity on national surveillance systems (17, 18).

    - ◆ Sexual orientation/gender identify has been identified as a risk factor for suicidal behavior in multiple studies yet isn't routinely collected in national systems (19, 20).

- Improve the ability to monitor changes at the regional, state or county level or among subpopulations

  - Support enhancements to existing mortality and morbidity data systems to expand the geographic scope to include areas where data are not currently collected or to oversample underrepresented groups.

- Improve the timeliness and quality of information from death certificates.

  - Develop guidelines for medical examiners, coroners, and others who investigate and certify deaths in order to standardize the investigation of suicides and possible suicides.

  - Identify the systems and processes in states with timely death registration and reporting to develop best practices and serve as a model for other states.

  - Ensure that all states have the resources (e.g., funding, trained staff) to implement electronic death registration systems that feed into the national vital statistics system.

  - Investigate the feasibility of tracking national suicide mortality on a quarterly basis using mortality surveillance data from vital statistics (21).

- Endorse the use of external cause coding (a data element needed to identify suicide attempts) on medical records as a requirement for reimbursement by insurance carriers (22).

- Support inclusion of suicide-related items in data systems that capture "real time" information on hospital emergency department visits to improve the monitoring of trends in suicidal behavior.

  - Collection of "real-time" data (i.e., data made available to analysts immediately after the event occurs) improves the ability for decision makers to respond efficiently and rapidly to potential public health problems (23).

- Encourage all states to include nonfatal suicidal behavior (suicide attempts) by youth ages 12–17 as a health condition to be reported to the state health department (as per the Oregon model) (24).

  - In 1987 the state legislature in Oregon mandated that hospitals treating a child aged 17 years for injuries resulting from a suicide attempt report the attempt to the State Health Division, Oregon Department of Human Resources, and that the patient be referred for counseling.

Some of the recommendations proposed by the DSTF might be achievable in the short term (<1-3 years) by modifying existing data systems, while others involve more extensive

changes and might require longer term efforts (4-10 years). Short term recommendations, such as adding already identified valid and reliable questions to some national surveys or incorporating standard language in coding systems and national surveys, may be feasible because consensus documents exist that provide guidance on these issues (4, 13-15). Longer term recommendations such as standardizing death investigation practices across the United States or changing state health department requirements for reporting adolescent suicide attempts may require greater coordination, effort and support in order to be achieved.

The task force members believe that successful implementation of these recommendations will significantly enhance the development of a national coordinated program of fatal and non-fatal suicide surveillance. Such a coordinated program would facilitate evidence-based action to reduce the incidence of suicide and suicidal behavior in all populations.

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Table 1

Suicide-related systems reviewed, by category

Category	System Name	Website	Administering Organization
Deaths			
	Arrest-Related Death Survey	http://bjs.ojp.usdoj.gov/index.cfm?ty=tp&tid=82	Department of Justice, Bureau of Justice Statistics (BJS)
	Death Certificates from National Vital Statistics System	http://www.cdc.gov/nchs/nvss.htm	Department of Health and Human Services, Centers for Disease Control and Prevention (CDC)
	Deaths-in-Custody Reporting Program	http://bjs.ojp.usdoj.gov/index.cfm?ty=tp&tid=19	Department of Justice, BJS
	Department of Defense (DoD) Suicide Event Report (DoDSER – fatal section)	https://dodser.t2.health.mil/welcome	Department of Defense
	National Violent Death Reporting System (NVDRS)	http://www.cdc.gov/ViolencePrevention/NVDRS/index.htm	Department of Health and Human Services, CDC
Health care provider records			
	Adolescent Suicide Attempt Data System (ASADS) Oregon	http://public.health.oregon.gov/PreventionWellness/SafeLiving/SuicidePrevention/Pages/ASADS2.aspx	Oregon Health Authority Public Health Division
	Biosense	http://www.cdc.gov/biosense	Department of Health and Human Services, CDC
	Department of Defense (DoD) Suicide Event Report (DoDSER – nonfatal section)	https://dodser.t2.health.mil/welcome	Department of Defense
	Drug Abuse Warning Network (DAWN) (no longer operational)	http://www.samhsa.gov/data/DAWN.aspx	Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA)
	Healthcare Cost and Utilization Project (HCUP)	http://www.hcup-us.ahrq.gov/overview.jsp	Department of Health and Human Services, Agency for Healthcare Research and Quality
	National Ambulatory Medical Care Survey (NAMCS)	http://www.cdc.gov/nchs/ahcd.htm	Department of Health and Human Services, CDC
	National Corrections Reporting Program	https://www.ncrp.info/SitePages/Home.aspx	Department of Justice
	National Electronic Injury Surveillance System – All Injury Program (NEISS-AIP)	http://www.cpsc.gov/library/neiss.html	Department of Health and Human Services, CDC

Category	System Name	Website	Administering Organization
	National Emergency Medical Services Information System (NEMSIS)	http://www.nemsis.org	National Association of State EMS Directors, National Highway Traffic Safety Administration, Health Resources and Services Administration
	National Hospital Ambulatory Medical Care Survey (NHAMCS)	http://www.cdc.gov/nchs/ahcd/about_ahcd.htm	Department of Health and Human Services, CDC
	National Hospital Care Survey (NHCS)	http://www.cdc.gov/nchs/nhcs.htm	Department of Health and Human Services, CDC
	National Hospital Discharge Survey (NHDS)	http://www.cdc.gov/nchs/nhds.htm	Department of Health and Human Services, CDC
	National Suicide Prevention Lifeline	http://www.suicidepreventionlifeline.org	Department of Health and Human Services, SAMHSA
	National Survey of Prison Health Care	Website not available Report using data - http://static.nicic.gov/Library/015999.pdf	Department of Justice
	National Trauma Data Bank (NTDB)	https://www.ntdbdatacenter.com/	American College of Surgeons
	Resource and Patient Management System (RPMS)	http://www.ihs.gov/RPMS/index.cfm?module=home&option=index&CFID=14067134&CFTOKEN=48279019	Department of Health and Human Services, Indian Health Service
	Suicide Prevention Coordinator Reports	Website not available Report describing data - http://www.va.gov/opa/docs/Suicide-Data-Report-2012-final.pdf	U.S. Department of Veterans Affairs
Population-based surveys			
	Behavioral Risk Factor Survey System (BRFSS)	http://www.cdc.gov/brfss/	Department of Health and Human Services, CDC
	National Co-morbidity Survey (NCS, 1990-92) and Replication (NCS-R, 2001-3)	http://www.hcp.med.harvard.edu/ncs/instruments.php	Department of Health and Human Services, National Institute of Mental Health
	National Survey on Drug Use and Health (NSDUH)	http://www.icpsr.umich.edu/icpsrweb/SAMHDA/index.jsp	Department of Health and Human Services, SAMHSA
	Youth Risk Behavior Surveillance System (YRBSS)	http://www.cdc.gov/HealthyYouth/yrbs/	Department of Health and Human Services, CDC
	National Epidemiologic Survey on Alcohol and Related Conditions (NESARC)	http://niaaa.census.gov/	Department of Health and Human Services, National Institutes of Health
Health insurance claims			
	Medicare/Medicaid	http://www.cms.gov/Research-Statistics-Data-and-Systems/Research/ResearchGenInfo/index.html	Centers for Medicare & Medicaid Services

Table 2

Use of Existing Data Systems for Suicide-related Surveillance: Selected Strengths and Challenges by Data Source

Source: Death records
Purpose: Medico-legal and public health
Use for surveillance: To monitor mortality
Characteristics: Types include death certificates, autopsy reports and death investigation reports from medical examiners/coroners. Includes information on the manner and cause of death.
Examples: National Vital Statistics System, National Violent Death Reporting System (NVDRS)

Strengths	Challenges
• Intensive investigation by medical examiners/coroners for some causes of deaths (e.g., suicide)	• Death certificates capture limited information
• Intent of the injury is specified	• Death certificates cannot be easily modified due to the need to conform to national and international standards
• On-going data collection	• Processing of data, including assignment of codes for cause of death, can delay timeliness
	• Some demographic factors (e.g., race/ethnicity, veteran status) could potentially be misclassified because information is collected from next-of-kin or friends of the deceased
	• There can be variation among medical examiners/coroners in death investigation and certification practices

Source: Health care provider records
Purpose: Administration, billing, clinical care, referral to medical and behavioral health care, risk assessments and interventions provided by trained counselors
Use for surveillance: To monitor morbidity and provides details on patient history, early warning, case histories
Characteristics: Types include hospital in-patient and emergency department (ED) records, syndromic events, trauma registries, and Emergency Medical Service (EMS) reports. These records provide information on the clinical condition of the injured person and on patient care. Generally, the collection of information is secondary to other activities (e.g., delivery of patient care).
Examples: Healthcare Cost and Utilization Project (HCUP), National Hospital Ambulatory Medical Care Survey (NHAMCS), National Electronic Injury Surveillance System (NEISS), National Suicide Prevention Lifeline

Strengths	Challenges
• Narrative fields can provide more detailed information (e.g. NHAMCS)	• Limited to information available in the medical record
• Data are derived from existing records; no *de novo* data collection required	• Depending on the dataset, the number of records specific to suicide could be small
• Some data on charges or cost of care are available (e.g. HCUP)	• Comparison of data across systems can be difficult because systems may collect data in diverse formats or differ in how records are organized
• Includes geographic detail	• Timeliness can be an issue due to delays in processing administrative records
• Might be helpful for emerging health issues	• Key data elements are frequently missing or not collected (e.g., race, external cause of injury, circumstances of the injury event, risk/protective factors)
	• May only contain data on events or cases (numerator); rarely has information on the population at risk (denominator)
	• Generation of the surveillance data is not the primary function of the system that actually yields the data. Because the information is collected for other purposes, the use of standardized case definitions and the quality of the data collected can be challenging.

Source: Population-based surveys
Purpose: Monitor behaviors and/or health status
Use for Surveillance: To identify broad populations at risk for health effects
Characteristics: Involve well-defined, time-limited collection of information from the entire population (census) or a representative portion (sample). Can be designed to capture in-depth information on multiple topics. Surveys are excellent for providing baseline or 'snap-shot' data, however, use in monitoring trends requires repeated administration.
Examples: National Survey on Drug Use and Health (NSDUH), Youth Risk Behavior Survey (YRBS)

Strengths	Challenges
• Flexible, but changes to the structure of the survey (e.g., adding new questions) might take time • Anonymity of the respondent may promote truthful responses • Can be designed to focus on factors associated with suicidal behavior such as socioeconomic status • Timeliness	• Depending on the sample design, the ability to provide estimates for sub-populations might be limited • Can be expensive to administer • Analysis can be complicated if the survey uses a complex sampling design • Relies on self-report, which may be inaccurate • As response rates decline, selection bias may increase resulting in a reduction in the representativeness of the responses (particularly with telephone surveys) • Time/space constraints of survey administration may limit the number and types of questions that can be included

Source: Health insurance claims
Purpose: Financial administration
Use for surveillance: To monitor morbidity, provide details on medical history
Characteristics: Data are maintained by insurance organizations and used to process claims
Examples: Medicare, Medicaid

Strengths	Challenges
• Can detect small changes in the occurrence of events because of the large number of records • Both initial visit and outcomes can be tracked • May provide information on the patient's medical history prior to the event • May be able to track continuity of care • Timeliness	• The system is not designed for surveillance • Only the population of persons insured by the carrier are included in the dataset; patients who change insurance provider are no longer in the system • External cause of injury (used to identify suicide attempts) may be missing or limited • Access to the data may be limited depending on the affiliation of the user