

National Institutes of Health Pathways to Prevention Workshop: Advancing Research to Prevent Youth Suicide

Todd D. Little, Ph.D.^{1,¥}, Kathleen M. Roche, Ph.D.², Sy-Miin Chow, Ph.D.³, Anna P.
Schenck, Ph.D.⁴, and Leslie-Ann Byam, M.A.⁵

¹Institute for Measurement, Methodology, Analysis, and Policy, Department of Educational Psychology and Leadership, Texas Tech University, Lubbock, TX; ²Department of Prevention and Community Health, Milken Institute School of Public Health, The George Washington University, Washington DC; ³Department of Human Development and Family Studies, College of Health and Human Development, The Pennsylvania State University, State College, PA; ⁴North Carolina Institute for Public Health, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC; ⁵Families First, Evidence-Based Associates, Washington, DC.

¥Corresponding Author:

Todd D. Little, Ph.D.
Director, Institute for Measurement, Methodology, Analysis, and Policy
Professor, Educational Psychology at Texas Tech University
Coordinator, Research, Evaluation, Measurement, and Statistics (REMS) Concentration
3008 18th Street
Texas Tech University
Lubbock, TX 79409
yhat@ttu.edu

Abstract

The National Institutes of Health (NIH) Pathways to Prevention Workshop: Advancing Research to Prevent Youth Suicide was co-sponsored by the NIH Office of Disease Prevention, the NIH National Institute of Mental Health, the National Institute on Drug Abuse, and the National Center for Complementary and Integrative Health. A multidisciplinary working group developed the agenda, and an Evidence-based Practice Center prepared an evidence report that addressed data systems relevant to suicide prevention efforts through a contract with the Agency for Healthcare Research and Quality. During the workshop, experts discussed the body of evidence, and participants commented during open discussions. After considering the data from the evidence report, expert presentations, and public comments, an independent panel prepared a draft report that was posted on the NIH Office of Disease Prevention website for five weeks for public comment. This final report provides a roadmap for optimizing youth suicide prevention efforts by highlighting strategies for guiding the next decade of research on youth suicide. Strategies include recommendations for improving data systems, enhancing data collection and analysis methods, and strengthening the research and practice community.

Introduction

Suicide is the second leading cause of death in youth (10 to 24 years of age) and young adults (25 to 34 years of age), claiming the lives of 12,073 individuals in these age brackets in 2014 (1). Risk factors (e.g. depression, mental disorders, substance abuse, prior attempts, family history of suicide, family violence, exposure to suicidal behavior, incarceration), precipitating events (e.g. shame, loss, relationship disruption), and environmental circumstances (e.g. access to lethal means) highlight the multiplicity of factors contributing to suicidal behavior and reveal the challenge of developing interventions to attack this enduring and growing public health concern.

Suicide exacts tolls on family, friends, community, and society, as well as the individual; it reflects a biopsychosocial mix, including depression, disillusionment, desperation, and despair along with the influences of peers, families, and communities. The changes caused by suicide are layered. There are financial costs for society and families, and a profound emotional loss for those left behind. At the individual level, changes span the hard road to recovery or death.

More than 41,000 Americans die from suicide each year. It's the tenth leading cause of death in the United States. Though daunting, the obstacles created by the complexity of factors involved in suicide prevention are surmountable, and suicide prevention is possible. This complexity must be embraced to forge new research strategies. Many promising research avenues exist, but they are not coordinated. On March 29–30, 2016, the National Institutes of Health convened a Pathways to Prevention Workshop on Advancing Research to Prevent Youth Suicide. The overarching goal of the workshop was to summarize youth suicide prevention efforts. The workshop was co-sponsored by the NIH Office of Disease Prevention, the NIH National Institute of Mental Health, the National Institute on Drug Abuse, and the National Center for Complementary and Integrative Health. A multidisciplinary working group developed the agenda, and an Evidence-based Practice Center prepared an evidence report that addressed data systems relevant to suicide prevention efforts through a contract with the Agency for Healthcare

Research and Quality. During the workshop, experts discussed the evidence and participants commented during open discussions. After considering the evidence report, expert presentations, and public comments, an independent panel prepared a draft report that was posted on the NIH Office of Disease Prevention website for five weeks for public comment. This draft report summarized the workshop and identified research gaps and future research priorities. This report provides a roadmap for optimizing youth suicide prevention efforts by highlighting directions for guiding the next decade of research on youth suicide. These directions, summarized in Tables 1–3, are organized around three larger issues: improving data systems, enhancing data collection and analysis methods, and strengthening the research and practice community.

Improving Data Systems

Table 1 shows recommendations for improving data systems that focus on better identifying persons at risk and advancing knowledge of risk factors. As noted in the evidence report, the availability of effective data systems for examining suicide risk and outcomes is limited. The authors conclude that only 6 of the 153 suicide prevention studies linked suicide data from multiple sources, limiting researchers' capacity to study determinants, mediators, and moderators of suicidal behaviors and suicides as outcomes. The lack of data linkages impedes valid conclusions about suicidal behavior. Moreover, research on youth suicide is typically underpowered, particularly when the multiple determinants, mediators, and moderators are considered. Poor documentation of interventions (e.g., scarcity of usable data dictionaries and comprehensive clinical records) compounds the problem of inadequate data systems. For example, the U.S. Preventive Services Task Force concluded that there is insufficient evidence to assess the balance of benefits and harms of screening for suicide risk in adolescents, adults, and older adults in primary care. The lack of comprehensive, linked data resources makes it difficult to identify those at risk of suicide.

A workshop speaker noted that the ability to understand the magnitude of the problem and the factors influencing suicide and suicide attempts is hampered by not using cause-of-injury codes in medical departments and on insurance claims. Not all states mandate the use of these diagnostic codes. A complete picture of suicide and related factors would require federal mandates for health care providers to use external cause-of-injury codes. Improved standardization and consistent use of cause-of-injury coding would enable researchers to conduct more accurate studies of suicide risk and prevention. Additional surveillance on suicides is clearly needed. The National Violent Death Reporting System provides an example of a surveillance system that could yield insights into causes and context of suicides by linking data from death certificates, law enforcement reports, crime laboratories, and medical examiner reports. These data are not present in all states, and the reporting only addresses deaths from suicide, not suicide

attempts and related behaviors. Without additional mandatory coding, it is not possible to determine if the death was a homicide, suicide, or an accident. Implementing mandatory cause-of-death coding would enable public health officials and prevention science researchers to capitalize on these data to identify means of suicide. This recommendation is paramount, as more than half of the reported suicides employ firearms as the means, which supports our recommendation that a percentage of research, prevention, and interventions focus on the means of suicide. Linking with existing surveillance and administrative data should be encouraged, but training is needed to help researchers identify and obtain permission to use data sources found in school, municipal, state, and federal records (e.g., making sure consent forms explicitly ask permission to link with other data sources).

Policies at the state and community levels share a role in improving our ability to understand suicide and suicide attempts. State all-payer claims databases could provide communities with local data about suicide and suicide attempts. Under the Affordable Care Act, accountable care organizations or health information exchanges could provide local communities with population data. Claims databases can be cumbersome, require extensive cleaning and specialized expertise to analyze, and are not always timely. Some of these limitations can be addressed through coordinated efforts at the state level. By improving these systems, states have the opportunity to be innovative with syndromic surveillance data, which could be used to identify patients in need of improved care management, or used by communities to help target interventions.

A number of policy and practice issues are perhaps the most difficult of the problems to rectify due to social stigma, governance, conflicting legal goals, a fragmented death scene investigation system, silos of isolated research teams, and unique data systems. For example, we will not have accurate reporting until we de-stigmatize suicide and mental health issues. Reporting and tracking suicidal behavior and its precursors are hampered by disincentives embedded in policies and practices from the federal to the local level. Families and medical providers often are reluctant to

label events as suicide or suicide attempts for a number of reasons, including legal concerns, cultural issues, community referral patterns, and the lack of standard procedures for investigating suicide death scenes.

Table 1. Recommendations for Improving Data Systems

| | |
|---|---|
| 1. Improve the ability to identify persons at risk for suicide events. | |
| | A. Develop and implement standardized measures generalizable across settings, communities, and cultures to identify those at high risk for suicide. |
| | B. Mandate use of cause-of-injury codes so that suicides and suicide attempts that require medical attention can be identified. |
| 2. Improve the ability to understand protective and risk factors of suicide. | |
| | A. Expand surveillance of suicide and suicide attempts by linking data from multiple sources (e.g., state all-payer databases, syndromic emergency room data, electronic health records data, health information exchanges, accountable care organizations, research data). |
| | B. Encourage and facilitate efforts to document implementation and measurement details (e.g., code books, data dictionaries). |
| | C. Use broad measurement strategies that will improve measurement of ecometrics and psychometrics. |

Improving Research Design and Analysis

Table 2 depicts the panel's recommendations for improving research design and analysis of complex systems. Descriptions of several innovative and promising techniques follow.

Conduct measurement at multiple levels. An especially ripe area for improving data systems in the realm of suicide prevention research pertains to measurement. Measuring risk and protective processes at multiple levels—including the individual, family, peer group, school, and community—facilitates investigating and understanding the complex set of factors central to suicide risk across diverse populations. At the most micro level, information on biomarkers and biological processes is important for advancing the continuum of suicide research, from surveillance to basic research to prevention studies.

Novel ways of integrating neurobiological measures into the science of suicide prevention research are needed. One workshop speaker presented data that connects head injuries to risks for depression. It could be beneficial for school systems to collect electronic data on student head injuries and link these to school and health records to enhance identification of youth at increased risk for suicide. Biological measures may improve the effectiveness of evaluation research. Evidence for the protective effects of mindfulness and meditation practices, mentioned by suicide survivors at the workshop and supported by numerous studies, is strengthened by the inclusion of measures of biological mechanisms, such as reduced cortisol. Incorporating biological measures into studies of suicide risk and prevention will help identify potential treatment approaches for ameliorating the adverse impacts that trauma and stress have on youth suicide risk.

Psychological and developmental processes also play key roles in suicide risk and prevention. Speakers noted the need for psychometric work addressing the measurement of (a) personal characteristics such as sexual orientation and identity and (b) processes displaying universal prominence, as well as culture- and context-specific importance across diverse populations.

Rather than adapting existing measures to new cultural contexts, direct development of theoretically informed measures for a given cultural context is warranted.

For individuals identifying as sexual and gender minorities, measures of peer and self behaviors and attitudes salient to gender identity and sexual orientation can help to better identify these correlates of suicide risk. Research indicates higher rates of suicide among transgendered youth than among gay or lesbian youth. General methodological improvements in measurement, such as visual analog scales, computerized adaptive testing, and multiform questionnaire protocols to collect data would increase the reliability and validity of the findings.

Perhaps the least extensively investigated domain concerns measuring the settings and contexts beyond the individual and family levels. Ecometrics, the measurement of environmental contexts, is essential to accommodate the multilevel analytic approaches needed for this field of research. Innovation in this area includes direct assessment of constructs such as climate and aggregate indicators that can come from linkable administrative data (e.g. police records).

Assess developmental and longitudinal change. Despite the importance of dynamic change processes in youth suicidal behavior, few studies have addressed how changes and reciprocal influences among risk and protective factors influence youth suicidal behaviors across multiple time scales (short- and long-term changes). Longitudinal information is lacking about the processes and provider practices occurring among suicidal youth, particularly immediately preceding a death by suicide. Our capacity to design interventions aimed at preventing suicide depends on longitudinal research that can better capture the complex interplay among imminent and long-term factors in predicting suicide ideation and attempts.

By incorporating a broader repertoire of predictors into a longitudinal context—whether in a single study or through the use of linked studies (see below)—we are better positioned to understand the mediating, moderating, and reciprocal mechanisms underlying suicidal behavior. Studies integrating qualitative and quantitative data on these mechanisms will then better inform approaches to optimally time and maximize the impact of prevention efforts. For example, children

who question their gender identity may experience rejection from parents, teachers, or peers; rejection, in turn, may increase a child's social isolation and depressive symptoms that can further escalate rejecting behaviors.

Measurement and design strategies that facilitate the study of changes over time and across developmental periods will help inform the timing and targets for interventions that can interrupt the recursive cycle of negative social interaction. A growing body of evidence points to the potentially powerful effects of short-term predictors (e.g., insomnia, exposure to coping or self-regulation skills, peer support, intervening efforts from teachers, real-time sharing for care management) on longer-term suicidal prevention processes. Such cascading, multiple time scale effects offer a renewed way of conceptualizing and testing mediation and moderation, often at much lower long-term costs. To evaluate the long-term effects of intervention programs, we recommend that researchers collect and integrate measurements from multiple time scales, including measures of likely mechanisms of change. Integrating evidenced-based results with theory and methods will help ensure high-quality and effective suicide prevention efforts.

All of these modeling efforts are enhanced by using latent variable approaches to test critical assumptions, such as the psychometric equivalence of constructs across time and subgroups, and to correct important estimates for various sources of measurement and sampling error. At group and network levels, powerful methods exist for modeling important effects such as diffusion, contagion, selection, and socialization as well as propagation of risk or protective factors and associated processes.

Model multilevel structure. Compelling evidence exists for the multilevel nature of factors and processes tied to youth risk of suicidal behavior. Research rarely assesses and analyzes the interrelated and nested social processes and structures tied to suicide risk, particularly at higher levels of influence such as school, neighborhood, and community. Settings at a higher, more distal level (e.g., community), can have a cascade of effects on youth suicide risk by shaping family and individual functioning. Studies of multilevel effects on suicide risk suggest that

interventions addressing factors at the community and family levels may impact large numbers of individuals to a greater extent than typical individual-level interventions alone. Variations of universal intervention programs sensitive to multilevel structures should be designed and evaluated to effectively target individual, as well as higher-level risk factors (e.g. school, neighborhood, and community). Multilevel analytic techniques help adjust for issues of known clustering (e.g., families nested in communities) and thereby can capture the heterogeneity across multiple levels and cross-level mediation or moderation effects. Several methodological challenges must be addressed to estimate multilevel effects on youth suicide risk. These challenges also manifest in the measurement and design needs to represent adequately the different levels of a multilevel structure.

Examine known and unknown subgroups. Subgroups and subpopulations contribute to the heterogeneity of study cohorts. These subgroups can have differential effects and patterns of change. Methods to model known and unknown heterogeneity can identify and explicitly model these differential effects. When suicide-risk groups are known (e.g., groups defined by gender identity and orientation), the group membership can be represented as fixed effects to control for their influence. The groups also can be explicitly compared as multiple groups to examine various influences, including moderation by group membership. When subgroups are not explicitly known, the different suicide-risk subgroups and subpopulations that are often embedded in universal programs can be estimated. Mixture modeling identifies subgroups of individuals for whom an intervention may have differential influences. Predictors and outcomes of group membership can inform the differential impacts and outcomes of suicide prevention research.

Integrate and link data across studies. Another recommendation involves coordinating efforts in the broader research community. Integrative data analysis uses a set of common measures across two or more studies to link the data. These linked studies can be combined as an integrated data set that allows greater overall power to identify hard-to-detect mediating and moderating mechanisms, as well as greater representation of suicides, which are infrequent in

any given study or setting. Including common measures and linking items across projects, coupled with principled treatment of the missing data, would expand the power and validity of the larger research portfolio sponsored by funding agencies. The data archive of the National Institute of Mental Health is an important sharing platform for integrative data analysis, but the linking information must be coordinated and highlighted (<http://rdocdb.nimh.nih.gov>).

Employ stronger inference strategies. Randomized controlled trials (RCTs) have long been regarded as the “gold standard” through which valid inference can be accomplished. Although promising under some conditions, many RCTs are characterized by strict exclusion criteria that limit their generalizability for suicide-related research. Recent methodological advances, however, offer alternative methods to strengthen valid interpretations from non-RCT data. Propensity score methods can be used to study group differences, probe for unmeasured confounding effects, and infer aggregate effects in studies where random assignment is not possible. These methods also can be used to address selection effects inherent in mediator analyses in studies where the mediating mechanisms are not randomly assigned. Similarly, quasi-experimental designs such as the regression discontinuity design are quite relevant for suicide prevention research and may be used and expanded to deduce the effects of interventions. Cross-design synthesis also can be used to help combine RCT data and observational data. These designs facilitate valid inference based on targeted variables and can account for the effects of moderators across the range of studies. Importantly, multidisciplinary collaborations can integrate across the strengths from multiple techniques to overcome weaknesses and the restrictive assumptions of any single technique or study.

Meta-analysis is another powerful tool to help aggregate the effects of intervention programs across multiple studies. Results from meta-analysis not only help identify intervention components that are effective at the “average population level,” but also allow more effective quantification of the extent of uncertainty from one implementation to another—that is, for whom, to what extent, and for how long does an intervention program work. Meta-analysis can quantify the differences

in cost-to-benefit ratios and can be used to identify the ways in which universal and selective intervention components can be adapted to improve intervention efforts.

Table 2. Recommendations for Improving Design and Analysis

| | |
|---|---|
| 3. Design studies to ensure adequate coverage of data at multiple levels (e.g., family, school, community) and longitudinally (across time and the life course). | |
| | A. Move beyond a focus on individual-level data by collecting and analyzing multilevel data to represent effects over multiple levels. |
| | B. Use appropriate analytic methods to study cross-level moderation and mediation. |
| | C. Use broad measurement strategies that will improve measurement of econometrics and psychometrics. |
| | D. Utilize longitudinal methods to study dynamic and potentially reciprocal effects over multiple time scales (e.g., the effects of short- and long-term risk factors) and developmental periods. |
| | E. Incorporate person-centered methods to identify and model unknown heterogeneity in risk and protective factors and processes over time. |
| | F. Represent known heterogeneity, such as sex and race, explicitly (e.g., as fixed effects, multiple groups). |
| | G. Utilize latent variable approaches to test critical assumptions (e.g., measurement equivalence) and consolidate measures. |
| 4. Design studies and primary data collection efforts to facilitate data integration, linking, and pooling data across multiple studies. | |
| | A. Include a subset of common measures or linking items to integrate and pool data across studies. |
| | B. Model linked data from multiple sources (e.g., administrative and surveillance data). |
| | C. Incorporate information from multiple sources (e.g., teachers, schools, families, peers). |
| 5. Use principled, valid, and current missing data techniques (e.g., full information maximum likelihood, multiple imputation) to adjust for the effects of missing data mechanisms. | |
| | A. Design studies to ensure adequate coverage of baseline variables that may predict unplanned missing data. |
| | B. Use planned missingness designs as a cost-effective way to ensure adequate sampling and measurement coverage. |
| 6. Broaden methods for drawing valid conclusions to inform policy and practice. | |
| | A. Integrate information from RCTs and observational data (bias-adjusted models such as cross-design synthesis). |
| | B. Use techniques that improve the robustness and scientific rigor of studies in which randomization is not possible (e.g., modifications and extensions of quasi-experimental designs such as regression discontinuity and interrupted time-series designs; propensity score methods). |
| | C. Use meta-analysis to consolidate the strengths and identify the limitations of current intervention programs or implementation efforts. |

D. Use network and related methods to better understand group effects (e.g., diffusion, contagion, selection, socialization) as well as propagation of risk or protective factors and associated processes.

Building and Strengthening the Research and Practice Community

Table 3 provides recommendations for building and strengthening collaborative efforts among researchers, methodologists, and practitioners. Building a coordinated research and practice community would foster data linking, the translation of research to practice, and the dissemination of aggregated data needed for community planning. Coordination in the research community would need to occur at multiple levels, including in requests for proposals, in pre-award discussions with program officers, and in cross-project sharing among the various principal investigators of the funded research. Coordination also would need to occur in the coupling of administrative data from the practice community.

Interdisciplinary collaboration is critical to identify those at highest risk for inclusion in targeted prevention efforts (both universal and indicated approaches). Youth who die by suicide may not have had prior contact with mental health providers; however, they may have been seen by educators, medical providers, coaches, and other community members. Research identifying effective policies, such as gun control, to prevent means to suicide events is needed. Similarly, population-based efforts can and should draw on cross-sector collaborations (e.g., schools, law enforcement, parks and recreation departments, faith-based organizations) to strengthen protective factors in individuals, families, and communities. Recognizing the broader costs and impact of youth suicide is a critical policy agenda that can be addressed only by strengthening the larger community of researchers, practitioners, and stakeholders.

Finally, education and training opportunities and participation in them are needed to build and expand the research and practice infrastructure. Education of providers, agencies, families, and communities is needed to highlight the importance of removing the stigma associated with suicide. Improving messaging and social norms around mental health and suicide may help de-stigmatize suicide and promote connectedness within families and communities. Training in the advanced design and analysis techniques described above needs to be made readily available, and all members of collaborative teams should be given access to these training opportunities.

Broadening the understanding of the merits of using the recommended procedures highlighted by presenters at this Pathways to Prevention workshop is critical to bringing these procedures into the realm of standard practice.

Table 3. Recommendations for Building and Strengthening the Research and Practice Community

| | |
|--|---|
| 7. Encourage cross-sector collaboration—communication and the exchange of information, for example, among researchers, public health professionals, health care providers, law enforcement, policymakers, community organizations, and educators. | |
| | A. Increase research into policy and other approaches that restrict access to means of suicide (e.g., laws regarding open carry of firearms, state waiting periods and background checks before gun purchase, gun safety locks). |
| | B. Increase research into policy guidelines restricting access to information about suicide events (e.g., Health Insurance Portability and Accountability Act, Family Educational Rights and Privacy Act). |
| | C. Facilitate practitioners' ability to identify effective programs for their target groups by creating a menu of evidence-based suicide prevention programs with guidelines and descriptions of individuals/schools/communities that have benefited from the past prevention programs. |
| | D. Disseminate information on what works, what doesn't, to what extent, and in what context. |
| | E. Disseminate aggregated data for use in community prevention planning and evaluation. |
| 8. Provide education, training, and dissemination of research findings. | |
| | A. Promote awareness and understanding to reduce stigma associated with suicide. |
| | B. Educate health care professionals, parents, educators, and others who work with youth on current, new, and recurring issues related to youth suicide risk factors and prevention strategies. |
| | C. Encourage collaborative efforts among researchers, methodologists, and practitioners. |
| | D. Provide training opportunities for researchers and practitioners interested in using advanced methods to test theories. |

Conclusion

As researchers and practitioners, we must unite to stop youth suicide, and thereby circumvent the economic costs and the devastating pain and suffering it causes. We must build and strengthen both coordination and collaboration among all members of the larger policy, practice, and research communities. We must improve and coordinate the numerous surveillance and administrative data systems across these sectors. We must also elevate the level of rigor and breadth of methods directed to studies of suicidal behavior. Adherence to the recommendations summarized herein provides us with a roadmap directed to our ultimate goal: eliminate suicide.

1. Ten Leading Causes of Death by Age Group, United States – 2014. Accessed at Centers for Disease Control and Prevention at http://www.cdc.gov/injury/images/lc-charts/leading_causes_of_death_age_group_2014_1050w760h.gif on March 28, 2016.