Measuring Trauma: A Discussion Brief

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July 2016

Why Is Measuring This Construct Important?

- SAMHSA has a trauma and justice strategic initiative with the goal of understanding associations between trauma and mental health and substance use, and with the specific objective of creating a surveillance strategy for trauma and its association with mental and substance use disorders.
- Many trauma researchers distinguish between trauma meaning **exposure** to traumatic events (TEs) or potentially traumatic events (PTEs) and trauma meaning the **mental health consequences of exposure** (e.g., PTSD or other mental disorders that are caused or exacerbated by exposure to such events). It is clear that both PTE exposure and PTSD are important.
- Exposure to PTEs is a necessary but not sufficient condition to produce PTSD because there are numerous other psychosocial and biological risk and protective factors that can mitigate or exacerbate the risk of developing PTSD following PTE exposure. However, you cannot measure PTSD without measuring PTE exposure.
- There is substantial evidence from well-designed epidemiological studies indicating that PTE exposure is prevalent and that it increases risk of health problems and concerns as well as risk of numerous mental and substance use disorders.
- Other well-designed epidemiological research indicates that PTSD increases health risk behaviors, risk of morbidity and mortality, and risk of numerous other mental and substance use disorders.
- Other evidence indicates that individuals who have some PTSD symptoms but who do not meet full diagnostic criteria (i.e. those with partial PTSD/subthreshold PTSD/subclinical PTSD) have significant functional impairment and treatment needs.
- Accurate epidemiological data about PTE exposure and PTSD prevalence, as well as about the extent to which PTE exposure and PTSD status increase risk of other mental and substance use disorders, is an important gap in SAMHSA's current data collection efforts. Lack of accurate data makes it impossible to consider the prevalence of trauma-related problems when allocating mental health and substance use resources to states.

What Are the Data Needs?

SAMHSA provided useful information about the type of data it would like to be able to collect and indicates that it has been charged with:

- Defining and measuring trauma (e.g. to obtain national estimates of exposure to trauma and posttraumatic stress symptoms, including subclinical and clinical PTSD).

- Determining associations between trauma (i.e. PTE exposure using the DSM-5 definition of PTEs and PTSD symptoms) and mental health/substance use problems.
- SAMHSA describes its definition of trauma as including "three Es" of trauma (i.e., Event exposure, Experiencing of events, and Effects of trauma). However, the experiencing of events as traumatic appears to be a legacy of the DSM-IV PTSD Criterion A2 requirement that Criterion A1 events had to be experienced as producing fear, helplessness, or horror. This A2 requirement has been removed from the DSM-5 definition, so the authors believe that collecting data on how PTEs are experienced is no longer needed.
- SAMHSA would also like data on language spoken, race and ethnicity, gender, age, education, income, medical conditions, and health insurance status.
- SAMHSA indicates that national-level data are required every 3-5 years.
- Although SAMSHA did not address this point directly, the authors assume that data will be gathered using household probability sampling methods that do not include the chronically homeless or individuals who are in institutional settings (e.g., jails, prisons, nursing homes, long-term healthcare facilities). Special sampling and interview procedures would be needed to locate and interview individuals in these institutional settings.
- The authors also assume that data would be gathered from U.S. adults and adolescents age 12 and older because it would be less feasible to collect information on PTE exposure and PTSD from children under the age of 12.

What Dimensions Need to Be Measured?

- To obtain methodologically sound measures of the national prevalence of exposure to PTEs and PTSD using DSM-5 criteria, the minimal information required is assessment of exposure to all PTEs covered by Criterion A in the DSM-5 PTSD diagnosis, assessment of all 20 PTSD symptoms, and assessment of whether these symptoms produced distress/functional impairment. The assessment strategy is to first assess for PTE exposure and then to assess PTSD symptoms only among those with PTE exposure. Distress/functional impairment are assessed only among those who have several PTSD symptoms.
- According to the DSM-5, the Criterion A definition of a PTE is: "Exposure to actual or threatened death, serious injury, or sexual violence in one (or more) of the following ways: 1) directly experiencing the traumatic event(s); 2) witnessing, in person, the event(s) as it occurred to others; 3) learning that the traumatic event(s) occurred to a close family member or close friend; or 4) experiencing repeated or extreme exposure to aversive details of the traumatic event(s)". Examples of qualifying PTEs are described on pages 274-275 of the DSM-5 manual (APA, 2013).
- It is feasible to obtain methodologically sound epidemiological data on PTE exposure and PTSD measured using DSM-5 criteria from household probability samples of U.S. adults and adolescents. Measuring PTE exposure and PTSD symptoms has already been accomplished in numerous epidemiological studies of

household probability samples of adolescents and adults, most of which were cross-sectional but some of which were longitudinal. There are clearly challenges and details to be worked out, but they fall into the category of modifying and updating existing survey questions and measures to be consistent with DSM-5 criteria, not developing entirely new measures and questions from scratch.

- With respect to the types of events to be measured, at a minimum, one cannot measure PTSD using DSM-5 criteria without first measuring exposure to PTEs as defined in Criterion A of the DSM-5 PTSD diagnosis. However, this does not preclude measuring exposure to other potentially stressful life events (e.g., divorce, loss of job, nonviolent death of a loved one, physical illness, etc.). Nor does it preclude measuring exposure to adverse events that happened during childhood. We believe that a strong case can be made for measuring PTE exposure at a minimum because doing so is necessary to measure PTSD and then measuring other potentially stressful life events or adverse events if time, money, and space permit.
- Adequate measurement of PTE exposure cannot be accomplished via one or two gate questions but requires 20-25 behaviorally specific questions to ask about potential exposure to the broad array of PTEs. This approach has been used by several well-designed, well respected national epidemiological studies.
- If necessary, one option for PTE assessment that could reduce interview duration and associated costs would be to focus on PTEs that have been shown to have higher conditional probabilities of increasing PTSD risk. These include sexual violence and other types of violence involving physical assault, military combat or war zone experiences, and violent or accidental deaths of close relatives or friends. Measuring exposure to these PTEs is feasible and has already been done in major national surveys with adults and adolescents, but using behaviorally specific questions is essential to avoid serious underdetection of this type of PTE exposure.
- The tradeoff with this strategy is that it would reduce PTSD prevalence estimates because individuals with unmeasured PTE exposure would not be asked questions about PTSD symptoms. However, this limitation can be mitigated by adjusting for the impact of unmeasured PTE exposure on PTSD prevalence. This would require a preliminary study that measured exposure to all PTEs, assessed PTSD symptoms and distress/functional impairment, and then determined the impact of PTSD prevalence based on excluding questions about certain types of PTEs. Note: questions measuring the PTEs designated for exclusion should be placed after questions about the other PTEs to enable a determination of how many individuals would be skipped out. Also, it would be necessary to determine the overall impact of excluding these PTEs on PTSD prevalence.
- As we noted above, the "2nd E of trauma", or how the event is experienced, appears to be a legacy of the DSM-IV PTSD Criterion A2 requirement that events had to produce fear, helplessness, or horror. DSM-5 removed this requirement which simplifies measuring PTEs substantially in epidemiological studies because there is no need to determine whether experiencing these events produce these reactions. If SAMHSA wishes to determine whether PTEs, other potentially stressful events, or adverse events were perceived by respondents as being

traumatic or stressful, this can certainly be done by asking follow-up questions about each event that was experienced. However, this is not really necessary in order to determine whether exposure to different types of events increases risk of health concerns, health problems, or mental or substance use disorders. In an epidemiological study, measuring how different types of events are perceived by respondents would be an excellent candidate for the cutting room floor.

- All 20 PTSD symptoms must be measured in order to obtain information about partial/subclinical PTSD because all major operational definitions of this construct involve determining whether individuals meet some, but not all, of the PTSD Criterion B, C, D, and E symptom clusters. Unless individuals are asked about all symptoms within a cluster, it is impossible to determine whether they meet criteria for partial/subclinical PTSD.
- Unless data are collected about key mental or substance use disorders as well as about PTE exposure and PTSD status, it is impossible to determine whether PTE exposure and/or PTSD status increase risk of these mental or substance use disorders.
- The chief problems with the MHSS measurement of PTE exposure, PTSD, and subclinical PTSD were: 1) the SCID PTSD module used an inadequate measure of PTE exposure resulting in many individuals with actual PTE exposure being screened out of the PTSD symptom module; 2) respondents were not administered all of the PTSD symptom questions due to skip outs making it impossible to measure subclinical PTSD; 3) because of these two problems, estimates of PTE exposure, PTSD prevalence, and prevalence of subclinical PTSD were almost certainly substantial underestimates.

Methodological Issues and Trade-Offs

Good interview measures of PTE and PTSD diagnostic criteria exist that have been used in large scale household probability sample surveys of adults and adolescents. These measures have demonstrated feasibility and would require only minor modifications for use in future studies. However, there are other important methodological issues and tradeoffs.

1) Impact of sampling and data collection method on PTE exposure and PTSD prevalence estimates

- NSDUH uses in-person household sampling and in-person interviewers to collect data. ACASI (audio computer-assisted self-interviewing) is used for some sensitive topics. Advantages of this method are that it is the status quo, would require less change in current methodology, and could use ACASI for PTE and PTSD questions. Tradeoffs are that in-person interviewing is much more expensive than alternative methods (e.g., dual frame landline/cell phone RDD telephone or address-based sampling (ABS) with mail invitations that push respondents to the Internet for self-response with mail or telephone interview backup) and that the current NSDUH interview length cannot accommodate PTE and PTSD questions.

- Use of an ABS sampling strategy with a push-to-web, self-administered interview to measure PTE exposure and PTSD symptoms has numerous advantages which include substantially lower cost per interview and ability to use a highly-structured, self-administered version of a survey interview that provides the sense of privacy essential to maximize disclosure given the sensitive nature of content. Recent data indicate that approximately 84% of adults in the U.S. have internet access, so a tradeoff of this assessment method is that not all respondents can complete an online survey, potentially producing coverage error if the attributes of interest are distributed differently between those with and without internet access. However, paper versions of survey questions can be mailed to those who do not have Internet access to mitigate this coverage error.
- Web and paper are the preferable main data collection options (at least that do not involve an interviewer handing over a device for the sensitive questions), and web has many advantages including (for respondents) ease of navigating, ease of obtaining clarification/definitions, no need to keep track of a paper questionnaire, etc. and for researchers, no marginal cost per case, no data entry, easy to revise, timely response (no mail-back issues), no need to send an interviewer to the household.
- Response rates are generally lower for web than mail surveys but there is considerable variation, with web surveys sometimes producing higher response rates (see Tourangeau, Conrad & Couper, 2013, chapter 3). By conducting initial recruitment through mail, web response rates may well be comparable to mail response rates. Pre-notification can boost response rates in any mode and would be sensible to use here.
- Because increasingly many members of the U.S. population go online only via a mobile device, it is essential to accommodate mobile-only users. Because of this it is advisable to design for mobile and enable optimization for larger screens. Text message (e.g., SMS) pre-notification is particularly effective in boosting mobile participation, so it would be wise to collect email as well as phone contact information in the initial mail contact.

2) There are three key questions in terms of assessing DSM-5 mental disorders, including PTSD and substance use disorders in the context of large epidemiological studies: a) Is it essential to have clinicians using semi-structured clinical interviews to obtain good epidemiological data, or is it possible for lay interviewers using highly structured interviews to collect epidemiological data that are "good enough"?; b) Must interviews by clinicians or lay interviewers be conducted in person?; and c) Could all or part of interviews measuring mental disorders including PTSD and substance use disorders be self-administered?

- A key issue is whether it is necessary to use trained mental health professionals using semi-structured clinical interviews to measure these disorders. Using this methodology is extremely expensive, and, although often viewed as the "gold standard", there is a surprising lack of compelling data from epidemiological studies demonstrating that diagnostic prevalence estimates generated by clinicians using semi-structured interviews are more reliable or valid than diagnostic

prevalence estimates generated by lay interviewers using highly structured interviews. However, there are data indicating that clinicians and lay interviewers obtain similar results when using highly-structured interviews. This suggests that using trained clinical interviewers is required only if a semi-structured clinical interview is being used.

- Most large scale epidemiological studies (e.g. the NCS-R; World Mental Health Surveys; NESARC) have relied on lay interviewers using highly structured survey instruments to conduct face-to-face interviews in the respondents' homes. Other large scale epidemiological studies (e.g. the National Women's Study, the National Survey of Adolescents) have utilized lay interviewers with highly-structured interviews administered via telephone. The Mental Health Surveillance Study (a follow-on survey to the NSDUH) was conducted by clinicians via the telephone using a semi-structured clinical interview. As described above, the problematic estimates of PTE exposure and PTSD produced by the MHSS are largely attributable to problems with the semi-structured clinical interview, not that it was administered via telephone. Advantages of in person interviews are that they can be longer than telephone interviews and that in person interviewers can assist respondents with interview questions that are administered via CASI. The chief disadvantage of interviewing in person vs via telephone is the much greater expense of the former.
- Some studies use lay interviewers and completely structured interviews (e.g. the CIDI) to generate prevalence estimates and then do clinical re-appraisal studies with clinical interviewers using semi-structured interviews to calibrate prevalence estimates from the main study. Clinical re-appraisal studies are also expensive and involve considerable interaction between interviewers and respondents, which reduces privacy and willingness to disclose sensitive information. Tradeoff of not using this procedure is that some would be critical of prevalence estimates based on data not generated by clinicians. A major limitation of using clinician interviews is that it raises the cost substantially without substantially increasing the quality of the prevalence estimates.
- If the need for clinical interviewers using semi-structured interviews is taken off the table, then a viable option is to convert all or parts of highly structured interviews measuring mental or substance use disorders to a self-administered format using either a CASI platform in the case of in person interviewers or a web-based platform that could be accessed online. This would be considerably more cost effective and would enable larger sample sizes for less money.

3) Measure development and testing

Additional measure development work and testing may be needed, particularly to modify existing modules to be consistent with DSM-5, but as Terry Schell noted in his presentation at the National Academies of Sciences, Engineering, and Medicine workshop on measuring trauma,[1] an inventory of survey items

[1]National Academies of Sciences, Engineering, and Medicine. (2016). *Measuring Trauma: Workshop Summary.* K. Marton, Rapporteur. Committee on National Statistics and Board on Behavioral, Cognitive, and Sensory Sciences, Division of Behavioral and Social Sciences and Education. Board on Health

measuring exposure to an array of PTEs does not constitute a reflexive or effect-indicated measure (i.e. measures with items that are theorized to share a common cause). Therefore, many traditional measures of psychometric properties for such inventories are not appropriate. Establishing the temporal stability of responses to questions about PTE exposure is appropriate, as are measures of construct validity.

4) Recall bias

Although recall bias clearly exists, there are substantial data indicating that exposure to some types of PTEs can have long-lasting effects on mental and physical health and that respondents can remember and disclose exposure to these events even if they occurred many years ago. Telescoping, memory decay, and stigma may result in some loss of accuracy in reporting and disclosing exposure to these events, but there is also a downside to asking only about recent exposure to events.

5) Cross-sectional vs. longitudinal study design

We think it is important to recognize that it is possible to collect valuable information about PTE exposure, PTSD prevalence, and the extent to which PTE exposure and PTSD increase the risk of other mental and substance use disorders from cross-sectional studies. Although longitudinal studies are preferable, most relevant epidemiological cross-sectional studies have obtained information about lifetime exposure to PTEs as well as more recent exposure, and most studies obtain information about lifetime as well as current PTSD status. Looking at the proportion of those who ever developed PTSD (or other mental disorders) who have current PTSD (or other mental disorders) can provide some estimate of change of symptomatology over time. The issue of precisely tracking changes over time in mental or substance use symptomatology is precisely the same for PTSD as for other mental and substance use disorders.

6) Collecting data about PTE exposure and PTSD from adolescents

There have been good national epidemiological studies that have asked adolescent respondents about exposure to PTEs and PTSD. The National Crime Victimization Survey is an ongoing, longitudinal, large-scale survey that asks 12 to 17-year-old adolescents about exposure to PTEs involving physical and sexual assault as well as other violent crimes. The National Survey of Adolescents, National Survey of Adolescents-Replication, and the NCS-R Adolescent Supplement have all obtained information about PTE exposure and PTSD. Although there are human subjects' protection challenges, they have been successfully addressed in these and other studies. Bottom line: it is challenging

but feasible to collect these data from adolescents in national probability household surveys.

Design Options That Could Be Ruled Out

- Adding 3 to 5 questions to the NSDUH is not a feasible option because this would not permit proper assessment of PTE exposure, PTSD status using DSM-5 criteria, or determination of the relationship between PTE exposure and PTSD status on risk of other mental and substance use disorders.
- Although there are existing epidemiological data that address SAMHSA's objectives using DSM-IV diagnostic criteria, no comprehensive epidemiological data currently exist addressing these objectives using DSM-5 data. Therefore, using extant data to meet SAMHSA's data requirements is not a viable option.
- Collecting needed data via a follow-on module to the NSDUH is a potential viable option but only if substantial changes are made to the methodology utilized in the previous MHSS follow-on study (e.g., use lay interviewers instead of clinical interviewers; use highly structured interview modules instead of semi-structured clinical interview modules; use self-administration online mode to collect data about PTE exposure and PTSD as well as some other mental and substance use disorders).
- A new household survey conducted every 3 to 5 years that is designed especially to collect these and other needed data would be the best option, particularly if it were designed for multimode data collection and was not wedded to an in person data collection design. This would enable much larger sample sizes at much lower costs.

Suggested Next Steps

- In our judgment, SAMHSA needs to keep its primary focus clearly on measurement of PTE exposure, PTSD, and how they are related to risk of other mental and substance use disorders in epidemiological surveys and not get distracted by the question of how clinicians would assess these disorders in clinical treatment settings.
- Assemble a survey design team comprised of experts in measuring PTE exposure and PTSD in large scale epidemiological studies with adults and adolescents. Charge the team with reviewing extant survey modules measuring PTE exposure and PTSD and modifying them to produce highly-structured survey questions measuring PTE exposure and PTSD at the diagnostic level using DSM-5 criteria. The team should determine whether modified questions are needed for use with younger adolescents vs for older adolescents and adults.
- Develop and pilot test English and Spanish versions of four modules using these questions: a) an ACASI module for an interviewer-administered interview; b) an online, self-administered module for use with a probability panel recruited via ABS; c) a conventional CATI module; and d) a paper version of the module.

- Additional work is needed to define and operationalize the construct of partial/subthreshold/subclinical PTSD in light of expansion of the number of PTSD symptom criteria from three in DSM-IV to four in DSM-5. An expert consensus committee including representation from the V.A. National Center for PTSD could be established and charged with doing this.
- NOTE: A recently published article in *Social Psychiatry Psychiatric Epidemiology* by Goldstein et. al (2016) presented what were described as national prevalence estimates for PTSD using DSM-5 criteria derived from the NESARC III survey. However, close examination of the paper indicates that the authors used the wrong scoring algorithm for determining PTSD caseness. Specifically, the scoring algorithm required the presence of three Criterion D and three Criterion E symptoms instead of the two Criterion D and two Criterion E symptoms that are required in the DSM-5 diagnostic criteria. An inquiry with the authors of this paper was made, and the authors confirmed that the algorithm described in the paper was used to calculate PTSD caseness. The authors also stated that respondents who did not have at least one B, one C, three D, and three E symptoms were skipped out and not asked questions about onset, duration, or functional impairment. Consequently, the prevalence estimates in the paper are substantial underestimates of true DSM-5 prevalence, and all of the analyses comparing PTSD positive and negative groups on other diagnoses and outcomes are incorrect due to the misspecification of PTSD caseness. Furthermore, due to the skip out, it is impossible to determine DSM-5 PTSD prevalence using the NESARC data.