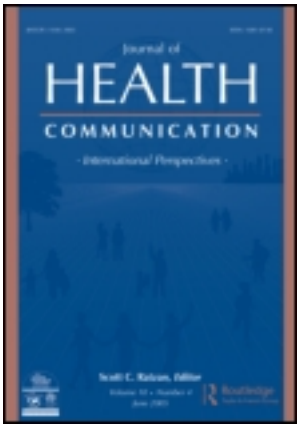

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The Need for Trauma-Sensitive Language Use in Literacy and Health Literacy Screening Instruments

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Commentary

The Need for Trauma-Sensitive Language Use in Literacy and Health Literacy Screening Instruments

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We would like to thank the clinical team at Massachusetts Mental Health Center for bringing our attention to this critical issue and helping us to continue to work for our research to be sensitive to the multiple needs of our participants. This work is supported by NIMH grant 1R01MH096707-01.

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The authors recently began a research study, funded by the National Institute of Mental Health, aimed at increasing the understanding of the ways in which limited literacy affects the lives of people with serious mental illness. In preparing for the study, the authors reviewed many health literacy screens and assessments for their appropriateness in public urban mental health settings. The Rapid Estimate of Adult Literacy in Medicine and the Test of Functional Health Literacy in Adults, perhaps the most frequently used assessments of health literacy, involve assessments that include lists of words that the test-taker must choose from or read. Each of these instruments includes language that is potentially triggering for trauma survivors, particularly those with posttraumatic stress disorder (PTSD). The research participants for the current project are consumers of mental health services, and thus, the authors believe it is essential to remove the problematic language, given that the likelihood of a diagnosis of PTSD and/or a history of abuse is higher than average among this population. However, the authors argue that this issue applies to anyone who administers these instruments, because sexual assault and abuse, as well as PTSD diagnoses, are certainly not confined to those who seek mental health services. The authors' aim is not only to call attention to the use of triggering language in existing literacy and health-related assessments and research instruments, but also to advocate that others take similar steps toward embracing more sensitive language by removing or replacing words that may cause unnecessary stress, anxiety, or pain to those who are at increased risk of retraumatization.

Although there has been increasing interest in the important relationships among literacy, health literacy, and health, few of these efforts have examined the impact of literacy or health literacy (heretofore referred to as *literacy*) on mental health and psychological well-being. Despite mounting endorsement of the goals of recovery for people with serious mental illness (SMI), mental health researchers have paid inadequate attention to understanding barriers to recovery. One such barrier is limited literacy. Although a growing body of literature focuses on literacy and a number of health outcomes (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Nielsen-Bohlman, Panzer, & Kindig, 2004), little work has been done to understand the ways in which literacy is related to psychiatric symptoms and diagnoses, mental health service utilization, quality of life, and participation in the community.

We recently began a research study, funded by the National Institute of Mental Health, called The Meaning and Impact of Limited Literacy in the Lives of People with Serious Mental Illness (principal investigator: Lincoln; 1R01MH096707-01), aimed at increasing our understanding of the ways in which limited literacy affects the lives of people with SMI. This mixed-methods study includes the conduct of structured and qualitative interviews. In preparing for the study, we reviewed many health literacy screens and assessments for their appropriateness in public urban mental health settings. We pilot-tested existing, validated instruments, such as the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA), or its short version (STOFHLA), with service users and providers in the clinics. In meetings with mental health clinicians at each site, our attention was quickly drawn to a concerning use of language in these instruments.

The REALM and the TOFHLA, perhaps the most frequently used assessments of health literacy, involve assessments that include lists of words that the test-taker must choose from or read. Each of these instruments includes language that is potentially triggering for trauma-survivors, particularly those with posttraumatic stress disorder (PTSD). For example, when taking the REALM, participants are asked to read aloud a list of words; this provides a means of assessing their ability to comprehend

patient education and other health-related materials, such as prescription labels. The test consists of three word lists, each containing 22 words. The last words on List 1 are *rectal* and *incest*. Thus, in practice, participants who take the test, with adequate literacy, must say aloud to the screener, "rectal incest."

The TOFHLA aims to assess health literacy using sentences that form a sort of narrative providing instructions about various medical situations. The test-taker must choose from a set of four words to fill in blank spaces in each sentence. One of the sentences assesses the participant's ability to comprehend the type of medical instructions that would be given to someone who is scheduled to have a stomach x-ray. The fill-in-the-blank question is stated as such: "You must have an _____ stomach when you come for _____." The choices for the first blank are: "a. asthma; b. empty; c. incest; d. anemia." Although *incest* is not the correct response option, the word is again included in the list of possible responses.

Exploring the use of standardized health literacy assessments for use with people with SMI in public mental health settings allowed us to view these instruments with a new and different lens. In these settings, there is a high level of awareness of the need for trauma-informed care, as people using public mental health services have often been exposed to high levels of trauma and experience increased rates of PTSD. Subica, Claypoole, and Wylie (2011) reported that individuals who experience SMI have high rates of exposure to trauma (between 61% and 98%) and prevalence of PTSD (ranging from 19% to 43%). In addition, they found that, among those with SMI, comorbid exposure to trauma and PTSD are associated with more severe depression and substance abuse, as well as lower overall mental and physical health (Subica et al., 2011).

PTSD occurs in some persons who are exposed to a traumatic event, such as incest, and is characterized by three symptom clusters: reexperiencing of the traumatic event; avoidance and numbing related to reminders of the trauma and overall hyperarousal. One of the reexperiencing symptoms is "physiologic reactivity upon exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event" (American Psychological Association, 2000). *Rectal incest* is clearly a potential external cue that could trigger distress in people with SMI who have trauma histories, particularly those with PTSD symptoms.

Trauma researchers use trauma-related words such as *incest* in a classic research paradigm called the Emotional Stroop test to study how people with PTSD differentially process information from those without the disorder (Foa, Feske, Murdock, Kozak, & McCarthy, 1991).

Put simply, the Emotional Stroop examines how words with specific types of content differentially capture attention and slow response time due to the emotional relevance of the word for the individual. Persons with PTSD show slower response times to trauma-related words, indicating these words have enhanced emotional content and interfere with information processing (McNally, 1998). Therefore, the use of trauma-related content in instruments designed to test literacy may unwittingly distress persons with trauma histories and, as a result of induced distress, interfere with obtaining accurate literacy assessments. Although there may be other health-related words on these assessments that could elicit an emotional response (such as *cancer*), we argue that trauma-related triggers are different than emotionally distressing words. The differences in reactivity we discuss are specific to individuals who have developed symptoms of PTSD. It is not simply having the experience (e.g., of a cancer diagnoses) that elicits the triggered response, but rather, it is experiencing psychiatric symptoms related to the experience that makes exposure to the word so potentially harmful.

After discussion among mental health service providers, psychologists, physicians, and academics, we decided modify the STOFHLA in our study by changing the word *incest* to *ingest*. We chose this word because it is applicable to health literacy and phonetically similar to *incest*. This creates a slight challenge for the project, as our version of the STOFLHA is slightly different from the validated and empirically tested one; however, we believe this modification is critical. Although we are not currently using the REALM, we suggest that researchers and practitioners implement a similar change, perhaps by also replacing *incest* with *ingest*, as well as replacing *rectal* with *renal*.

The research participants for our project are consumers of mental health services, and thus, we believe it is essential that we remove the problematic language, given that the likelihood of a diagnosis of PTSD and/or a history of abuse is higher than average among this population. However, we argue that this issue applies to anyone who administers these instruments, as sexual assault and abuse, as well as PTSD diagnoses, are certainly not confined to those who seek mental health services. Approximately 11% of Americans have been emotionally abused as children, whereas 28% have been physically abused and 21% have been abused sexually (Centers for Disease Control and Prevention, 2013). PTSD is a common disorder with a lifetime prevalence of 6.8% in the U.S. adult population (Kessler et al., 2005), and the majority of persons with PTSD do not seek mental health services (Roberts, Gilman, Breslau, Breslau, & Koenen, 2011).

Our aim is not only to call attention to the use of triggering language in existing literacy and health-related assessments and research instruments, but also to advocate that others take similar steps toward embracing more sensitive language by removing or replacing words that may cause unnecessary stress, anxiety, or pain to those who are at increased risk of retraumatization. We believe that, by modifying the instruments, what we may lose in validation pales in comparison with what we gain in creating a research environment that avoids unnecessary triggers and respects the dignity of the people who are willing to participate in our research. We hope that by opening this dialogue, we can encourage individual researchers and practitioners to make the same decision we did by replacing these words, as well as persuade those who are responsible for creating these and similar instruments to modify them so that they no longer include such controversial and potentially hazardous language.

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