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## Standardized Outcome Measures of Mental Health in Research with Older Adults who are Incarcerated

**Stephanie Grace Prost,**

University of Louisville

**Cynthia A. Golembeski,**

Rutgers University – Newark

**Vyjeyanthi S. Periyakoil,**

Stanford University

**Jalayne J. Arias,**

University of California – San Francisco

**Andrea K. Knittel,**

University of North Carolina at Chapel Hill

**Jessica Ballin,**

Oregon Health and Science University

**Heather D. Oliver,**

University of Louisville

**Nguyen Toan Tran**

University of Geneva, Switzerland

### Abstract

**Purpose:** The targeted use of standardized outcome measures (SOMs) of mental health in research with older adults who are incarcerated promotes a common language that enables interdisciplinary dialogue, contributes to the identification of disparities, and supports data harmonization and subsequent synthesis. We encourage researchers to use ‘gold-standard’ measures used in research with community-dwelling older adults, report associated study sample psychometric indexes, and detail any alterations in the approach or measure.

**Approach:** We highlight the mental health of older adults who are incarcerated. We also discuss the benefits of SOMs in practice and research, and then identify gold-standard measures of mental health used in research with community-dwelling older adults and measures used in research with older adults who are incarcerated. Finally, we provide several recommendations related to the use of SOMs of mental health in research with this population.

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**Correspondence:** Stephanie Grace Prost, Address: 2313 S 3 ST Louisville KY 40208, stephanie.prost@louisville.edu.

Conflict of Interest:

The authors have no potential conflict of interest in the research.

**Findings:** Depression, anxiety, and post-traumatic stress disorder are common among older adults who are incarcerated. Researchers have used a variety of measures to capture these mental health problems, some parallel to those used with community-dwelling samples. However, a more targeted use of SOMs of mental health in research with this population will contribute to important strides in this burgeoning field.

**Originality:** This review offers several practical recommendations related to SOMs of mental health in research with older adults who are incarcerated to contribute to a rigorous evidence base and thus inform practice, and potentially improve the health and well-being of this population.

### Keywords

Older adults; mental health; measurement; standardized measures; outcomes; incarceration

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Driven in part by longer and determinate sentencing structures and parole restrictions, older adults incarcerated in prisons comprise the fastest-growing age demographic within United States (U.S.) carceral settings. While COVID-19 has contributed to the release of many older adults (Finkle, 2021), the percentage of persons aged 55 and older sentenced under the jurisdiction of state or federal prisons increased 285% between 1999 and 2019 (Carson, 2000; 2020a). The imprisonment rate of this same age group in parallel jurisdictions also increased by 342% during the same period (Carson 2000; 2020a).

Scholars have documented increased physical, mental, and behavioral health comorbidities among older adults who are incarcerated when compared to their community-dwelling counterparts (Di Lorito *et al.*, 2018; Fazel *et al.*, 2001b; Skarupski *et al.*, 2018). As a result of the elevated mental health burden among this population, specifically, researchers are called to increase knowledge surrounding the causes, correlates, and consequences of mental health problems among older adults who are incarcerated both during and beyond the custodial stay. To this end, we encourage the targeted use of standardized outcome measures (SOMs) of mental health in research with older adults who are incarcerated.

In this review, we describe the mental health of older adults who are incarcerated, SOMs, and the benefits of SOMs in practice and research. We also identify several ‘gold standard’ measures of mental health used in research with community-dwelling older adults and measures used in existing research with older adults who are incarcerated. Finally, we provide several recommendations for researchers related to the use of SOMs of mental health in research with this population.

Specifically, we encourage researchers to embrace gold-standard measures used in research with community-dwelling older adults, report associated psychometric indexes for study samples, and detail any revisions to the measure or approach. We contend these strategies promote a common language which enables interdisciplinary dialogue, contributes to the identification of disparities, supports data harmonization, and allows for synthesis, thus contributing to a robust evidence base on which practitioners can draw. By extension, the use of SOMs of mental health in research with older adults may improve practice and subsequently, the health and social outcomes of older adults who are incarcerated during their detention, throughout reentry, and post-supervision.

## The Mental Health of Older Adults who are Incarcerated

Estimates of mental illness among older adults are varied. According to the 2019 National Survey of Drug Use and Health (NSDUH), 14% of U.S. adults aged 50 and older had any mental, behavioral, or emotional disorder, with 2.9% categorized as having a serious mental illness in the past year (Choi *and* DiNitto, 2021). Among those aged 55 and older, 20% to 23% experienced mental illness (Chapman *et al.*, 2005; Kogan *et al.*, 2000). And according to the Substance Abuse and Mental Health Services Administration [SAMHSA], 4.8% of U.S. adults aged 65 and older live with serious mental illness (SAMHSA, 2019). The three most common mental health problems among community-dwelling older adults are depression, anxiety, and substance use (Centers for Disease Control and Prevention [CDC], 2008; McCombe *et al.*, 2018).

Broadly, though, older adults who are incarcerated carry a heavier burden of mental health problems when compared their non-incarcerated, community-dwelling counterparts. Estimates of mental illness among older adults who are incarcerated range from 16% (Maschi *et al.*, 2011a) to more than 40% (Di Lorito *et al.*, 2018; Fazel *et al.*, 2001a). Such disparities are shaped by disproportionate traumatic experiences throughout the life course, economic deprivation, service barriers and deficient preventive and primary care, and carceral-specific factors including isolation, overcrowding, violence and victimization, and environmental stressors related to lighting, ventilation, and temperature (Bailey *et al.*, 2017; Ford *et al.*, 2019; Golembeski *et al.*, 2020; 2021; Stojkovic, 2007).

The role of racism in the mental health of older adults who are incarcerated must also be considered (Lewis *et al.*, 2015). Incarceration rates for persons of color are significantly higher than those of white, non-Hispanic persons and over 60% of persons who are incarcerated are people of color (Carson, 2020). Persons of color also endure disproportionate rates of arrest, detention, solitary confinement, and injury, illness, and death while incarcerated (Golembeski *et al.*, 2021; Massoglia, 2008). Institutional and interpersonal discrimination and oppression including microaggressions, limited structural competency, and race-related violence no doubt contribute to poor mental health outcomes among specific subsets of older adults, and thus, to health inequities (Metzl *and* Hansen, 2014; Davis, 2020).

Gender is also of critical importance regarding the mental health of older adults who are incarcerated. The incarceration rate for women has continued to climb and compared to men, aging women face distinct burdens. These include longer sentences, pronounced histories of poverty, violence, and trauma, elevated levels of chronic health problems, exacerbated menstrual and menopausal symptoms, and unmet needs regarding grief and loss (Bronson and Berzofsky, 2017; Handtke *et al.*, 2015; Jaffe *et al.*, 2021; Golembeski *et al.*, 2020). Substantial challenges are also likely present for older gender and sexual minorities, though too little research has been completed with these persons (Maschi and Morgen, 2020; Ba ak *et al.*, 2018).

## Mood Disorders

Depression is more common among persons with other illnesses, including chronic health problems and functional limitations (Cree *et al.*, 2020), which places older adults who are incarcerated at particular risk. Authors of a recent systematic review reported depression disorders affect 28% of older adults who are incarcerated compared to 7% of those in the community. Relatedly, nearly half of older adults with depression also endure anxiety. Anxiety affects 14% of older adults who are incarcerated compared to 4% of community-dwelling older adults (Di Lorito *et al.*, 2018). Anxiety may be due to multiple factors including age-related biological changes or the presence of a comorbid mental or physical illness (Kogan *et al.*, 2000); anxiety is also a critical risk factor of “near-lethal self-harm” among persons who are incarcerated (Fazel *et al.*, 2016).

## Substance Use Disorder

Broadly, the proportion of older adults aged 50 to 64 who used illicit drugs in the past month has increased from 4.1% in 2008 to 5.8% in 2013 (SAMHSA, 2014) and researchers predicted the number of U.S. adults aged 50 and older with substance use disorder would exceed 5.6 million in 2020 (Han *et al.*, 2009). According to case records from one state, nearly 81% of adults aged 55 and older who were incarcerated had substance use issues (Haugebrook *et al.*, 2010) and authors of a recent review detailed that between 5% and 80% of older adults who were incarcerated had substance use problems (Haesen *et al.*, 2019). In another study, roughly 27% of adults aged 45 and older self-reported issues with drug or alcohol use (Prost *et al.*, 2021). However, older adults who are incarcerated tend to report lower levels of substance use disorder than their younger peers (Gates *et al.*, 2017; Prost *et al.*, 2021).

## Post-traumatic Stress Disorder

Rates of PTSD are low among non-veteran, community-dwelling older adults. Prevalence rates range from less than 1% to 3%, though rates of partial PTSD are higher (7% to 13%; Averill *et al.*, 2000). However, authors of a recent meta-analysis revealed the prevalence of PTSD among men incarcerated in prison ranged from 1% to 27% and pooled prevalence estimates hovered near 6% (Baranyi *et al.*, 2018). In one study, 40% of adults aged 55 and older who were incarcerated in jail screened positive for PTSD (Flatt *et al.*, 2017). And in another study, roughly 33% of adults aged 45 and older who were incarcerated in prison met the clinical criteria for PTSD (Prost *et al.*, 2021).

## Standardized Outcome Measures

The substantial mental health burden and related disparities between older adults who are incarcerated and those in the community-dwelling warrants study and subsequent intervention. Key to such research, we contend, is the targeted use of standardized outcome measures (SOMs). For the purposes of this review, SOMs are defined as tools that offer witness to health-related functioning, performance, or participation (Gliklich *et al.*, 2020; Jackson 2020; Leavy et al. 2020; Duncan and Murray, 2012). ‘Gold-standard’ SOMs are those measures used in practice or research settings that have undergone comprehensive development and validation and have emerged with well-established psychometric indexes.

Most critically, such tools should demonstrate adequate reliability and validity, sensitivity to change, and have accessible, established norms for various populations and settings (e.g., typical/atypical; healthy/impaired; American Educational Research Association *et al.*, 2014; The Kennedy Forum, 2015).

These indexes often require that tools have undergone extensive study with large, heterogeneous samples and a variety of populations (e.g., age, race, gender, sex and sexuality), and across numerous settings (e.g., carceral/clinical/non-clinical). Tools that have undergone such efforts are also less likely to demonstrate floor and ceiling effects (viz. > 15% scores falling in the lowest or highest response options), evidence that a tool may have failed to some extent to capture a person's experience (Archuleta *et al.*, 2021).

Nomothetic approaches to measurement like SOMs have been cited as potentially limiting patient empowerment (Ashworth *et al.*, 2019; Trujols *et al.*, 2020). Too, scholars have offered some critique of the use of gold-standard measures in carceral settings (see Prost *et al.*, 2019). While some noteworthy exceptions exist, measure development and validation often begin with conceptualization and operationalization in the 'ivory tower,' risking the import of implicit bias. Also, SOMs are often completed independently (viz. self-report) which may contribute to measurement error when respondents do not understand instructions, questions, or response options. Yet, tools that enable stratification and classification of persons who are incarcerated remain critical to treatment (Fazel *et al.*, 2016). And while SOMs should not serve as the sole measure of a person's experience (Glenny *et al.*, 2018; Trujols *et al.*, 2020), they are integral in practice and research (Donabedian, 1988).

### SOMs in Practice

In clinical practice, SOMs are used to screen, diagnose, establish baseline and ongoing signs and symptoms, and evaluate care quality. As a result, groups such as the Joint Commission (2021) require the employ of SOMs to assess individual outcomes (CTS.03.01.09; Joint Commission, 2018). The Joint Commission also contends the capture and review of data from SOMs aids in the identification of care failure. SOMs are also often essential to coding and billing processes and may be required to demonstrate evidence-informed practice (Duncan and Murray, 2012; Unsworth, 2011).

The regular use of SOMs can aid in clinical decision-making through the identification of care strengths and weaknesses (Hostetter and Klein, 2012). The completion of SOMs by individuals receiving care may also offer direct benefit, providing ready witness to change (Joint Commission, 2018) most especially when completed and reviewed during care encounters (The Kennedy Forum, 2015). Practitioner-patient discussion of performance may also support therapeutic relationship building and thus improve care quality and future outcomes, a critical opportunity in prisons and jails considering issues surrounding trust in carceral health services (National Academy of Sciences, 2014). SOMs are also essential to intervention evaluation (Duncan and Murray, 2012; Fazel *et al.*, 2016; Haesen *et al.*, 2019; Moreau and Wiebels, 2021).

SOMs are important supports in carceral health practice, specifically. For example, persons who are incarcerated may first become aware of health problems during a custodial stay (Binswanger *et al.*, 2012). Many state Departments of Correction screen for tuberculosis, cardiovascular risk factors, hepatitis, traumatic brain injuries, mental illness, substance use disorder, and suicide risk during the admissions process (Chari *et al.*, 2016). The use of SOMs would also support continuity of care by aiding in translation between carceral and community-based practitioners for procedures, during inpatient hospitalizations, and upon release. Targeted intervention—informed by SOMs—during a custodial stay may also decrease burden among community healthcare systems by reducing physical, mental, and behavioral health problems among persons preparing for community return.

### SOMs in Research

Of primary concern for the current review, however, SOMs are essential to rigorous research. SOMs offer a common language, contributing broadly to the capture and creation of reliable and valid data on persons with criminal-legal system involvement and among older adults, especially (Ahalt *et al.*, 2012; Ahalt *et al.*, 2013; Binswanger *et al.*, 2019; Prost *et al.*, 2019). This common language 1) enables interdisciplinary dialogue, 2) contributes to the identification of disparities, 3) supports data harmonization, and 4) allows for subsequent synthesis. These mechanisms aid in the building of a solid evidence base, research that can then be used to inform practice (i.e., translation). Evidence-informed practice may therefore contribute to improved care and thus, increased health and well-being among this population (Gatherer, 2007).

A common language is essential to enabling interdisciplinary dialogue. Shared conceptualization and operationalization are first steps in meaningful collaboration and the resolve of complex social problems (Choi and Pak, 2007; Glenny *et al.*, 2018). Because of the unique constellation of both age-related and criminal-legal system considerations for older adults who are incarcerated, interdisciplinary approaches will be essential to research broadly and to the development, implementation, and evaluation of interventions across individual-, institution-, and community-levels (Maschi *et al.*, 2013). Scholars across varying professional disciplines including gerontology and geriatrics, pharmacy, criminology, sociology, social work, and public health will be integral to innovative supports for this vulnerable group both behind bars and beyond.

Within and between group comparisons are more readily made with a common language. This is of critical consideration due to racial and gender differences noted previously. Duran and colleagues (2019) note that the tackling of health inequities rests on quantifying health. And to quantify health requires a consensus regarding indicators. For this reason, groups such as the Panel on Cost-Effectiveness in Health and Medicine and the Consolidated Standards of Reporting Trials (CONSORT) have instituted consensus building efforts to identify and promote key measures for use and reporting.

The embrace of a common language also supports data harmonization. The limited collection and dissemination of health data among persons in carceral settings remains problematic (Ahalt *et al.*, 2013; Binswanger *et al.*, 2019; Prost *et al.*, 2019). This is especially important given the small number of datasets inclusive of individual-level data



of older adults who are incarcerated (Ahalt *et al.*, 2013). Further, available data from persons who are incarcerated may be less reliable or valid due to low trust in staff (Novisky *et al.*, 2021), limited understanding of one's experience, or internalized oppression (Porter, 2019). Stigma on behalf of the provider may also shape perceived or actual dual loyalty to patients and prison authorities (Glowa-Kollisch *et al.*, 2015) which can also influence validity. Thus, efforts to combine smaller, regional datasets using SOMs will be essential to advancing our understanding of the causes, correlates, and consequences of mental health problems among older adults who are incarcerated throughout their criminal-legal system involvement. For example, the National Commission on Correctional Health Care (NCCHC) created the Correctional Health Outcomes and Resource Data Set or CHORDS (NCCHC, 2019). This national performance measurement system is designed specifically to support the comparison of clinical processes and outcomes.

Researchers' use of SOMs would also contribute to synthesis via systematic reviews and meta-analyses (Duran *et al.*, 2019), allowing for the distillation of findings across multiple studies with fewer risks. For example, Puhan and colleagues (2006) note that researchers should employ caution when calculating effects across different instruments in meta-analysis even if they claim to measure similar constructs. While emerging correlations were large, researchers reported disparate responsiveness across quality of life measures which could attribute inaccurately variability to patient or intervention differences (*viz.* over- or underestimation of effect; Puhan *et al.*, 2006). With these mechanisms in mind, we next identify key SOMs of several mental health problems used in research with older adults in the community and those used in research with older adults in carceral settings.

## **SOMs of Mental Health in Research with Older Adults who are Incarcerated**

Multiple researchers have decried little agreement exists regarding which tools be used to capture mental health problems among the general population and older adults, specifically (Breedvelt *et al.*, 2020; Edelstein *et al.*, 2007; Scogin, 1994; Therrien and Hunsley, 2012). However, several scholars and professional organizations have put forth recommendations related to the capture of mental health in research with older adults. While the following does not represent a systematic review, we identify common and well-established measures of mental health used in research with community-dwelling older adults highlighting and measures used in research with older adults who are incarcerated.

### **Depression**

Breedvelt and colleagues (2020) note the Center for Epidemiological Studies Depression Scale (CES-D) is the most-often employed SOM for depression. For older adults, however, the American Psychological Association (APA) recommends the Geriatric Depression Scale (GDS; APA, 2019) and authors of a recent literature review also support the GDS and its abbreviated form, the GDS-15, as preferred (Balsamo *et al.*, 2018). Depression has been captured among older adults who are incarcerated using the GDS (Bishop *et al.*, 2014; Meeks *et al.*, 2008; O'Hara *et al.*, 2016). Though other measures including the CES-D (Allen *et al.*, 2013; Colsher *et al.*, 1992), the Patient Health Questionnaire-8 (PHQ-8; Prost *et al.*, 2021), the PHQ-9 (Barry *et al.*, 2020), the Hopkins Symptom Checklist (Deaton *et al.*,

2010), and the Geriatric Mental State (GMS) schedule (Fazel *et al.*, 2001a) have also been used. The depression subscale of the Brief Symptom Inventory (BSI) has also been used in research with this population (Allen *et al.*, 2008).

### **Anxiety**

Authors of one review found that 91 distinct measures had been used to capture anxiety among older adults, while only three held psychometric promise: the Beck Anxiety Inventory, Penn State Worry Questionnaire, and the Geriatric Mental Status Examination (Therrien and Hunsley, 2012). We did not locate these measures in existing research with older adults who are incarcerated. Instead, anxiety has been captured using the Diagnostic Interview Schedule (DIS; Koenig *et al.*, 1995), the 7-item General Anxiety Disorder scale (GAD-7; Vogel and Barry, 2019), the Hopkins Symptom Checklist (Deaton *et al.*, 2010), the Brief Symptom Inventory (BSI; Allen *et al.*, 2008; Kopera-Frye *et al.*, 2013; Phillips *et al.*, 2009), and the Geriatric Mental State Examination -- Automated Geriatric Examination for Computer Assisted Taxonomy (GMS-AGECAT; Fazel *et al.*, 2001a; Kingston *et al.*, 2011).

### **Post-traumatic stress**

Averill and colleagues (2000) note that assessment and treatment research related to PTSD rarely includes a proportional number of older adults. Further, the capture of PTS and PTSD among older adults is often complicated by cognitive impairment, sensory decline, and comorbid physical and mental health problems—all disproportionately prevalent among older adults who are incarcerated. However, the Clinician Administered PTSD Scale for the DSM-5 (CAPS-5) is often cited as the gold-standard measure of post-traumatic stress (Hunt *et al.*, 2018), though numerous self-report measures exist and have undergone multiple validation efforts (Steel *et al.*, 2011).

PTS and PTSD among older adults who are incarcerated has been captured using the Primary Care PTSD (PC-PTSD) screen (Flatt *et al.*, 2017) and the PTSD checklist for the DSM-5 (PCL-5; Maschi *et al.*, 2015; Prost *et al.*, 2021). Relatedly, exploration of traumatic experiences with older adults who are incarcerated has been completed using several measures including a modified version of the Stressful Life Experiences Screening Inventory-Long Form (SLESI-L; Maschi *et al.*, 2011b), the Life Events Checklist (LEC; Prost *et al.*, 2021), and the Life Stressors Checklist (LSC-R; Morrissey *et al.*, 2012).

### **Recommendations for Researchers**

SOMs offer benefit in practice and research settings, the most critical of which we argue is the promotion of a common language. This common language, in turn, aids interdisciplinary dialogue, disparity identification, data harmonization, and synthesis. We recognize many considerations shape the use of SOMs of mental health such as cost, length, familiarity, ease of interpretation, and researcher preference. Research design will also govern the embrace of some measures over others (e.g., self-report, face-to-face interview, proxy response). Some SOMs of mental health used in research with community-dwelling older adults are also used in research with older adults who are incarcerated, however, we put forth three specific



recommendations to further contribute to a rigorous knowledge base to inform and improve practice in carceral settings and to potentially improve outcomes among this population:

1. Employ measures parallel to those used in existing research with older adults in community-based settings
2. Report study sample measures of reliability, validity, skewness and kurtosis, and floor and ceiling effects
3. Report details regarding modifications to the measure or approach including administration method (e.g., self- versus proxy-report), instructions, question wording, response options, and scoring strategies

The use of SOMs of mental health in research with older adults is only one facet of a larger research thrust. While the proportion of funded research regarding older adults who are incarcerated remains small (Ahalt *et al.*, 2015), the field has gained increasing attention, spearheaded in large part by the National Institute of Aging (NIA) Aging Research in Criminal Justice Health (ARCH) Network. These and other scholars are encouraged to undertake a systematic review of existing measures used to capture physical, behavioral, and mental health and well-being among older adults who are incarcerated.

And because of limits associated with SOMs, several additional areas of research are indicated. Explorations of measurement feasibility and fit are warranted, beginning with psychometric study of gold-standard measures in these settings. For example, scholars are encouraged to examine model-data fit and measures of reliability and validity of seminal measures across subsets of older adults across age cohorts, race, gender, sex, and sexuality. The embrace of older adults as experts in the conceptualization, validation, and use of SOMs in these settings is also an important area for future research. Strengthened using expert panels, small-group interviews, focus groups, or member-checking, older adults may offer critical insights regarding key mental health constructs in the carceral milieu (Prost *et al.*, 2019). Further, our call to researchers cannot be disentangled from much needed intervention efforts related to mental health during and beyond the custodial stay.

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