


Serious Mental Illness in the Nursing Home Literature: A Scoping Review

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Abstract

Nursing homes (NH) and other institutional-based long-term care settings are not considered an appropriate place for the care of those with serious mental illness, absent other medical conditions or functional impairment that warrants skilled care. Despite policy and regulatory efforts intended to curb the unnecessary placement of people with serious mental illness (SMI) in these settings, the number of adults with SMI who receive care in NHs has continued to rise. Through a scoping review, we sought to summarize the available literature describing NH care for adults with SMI from 2000 to 2020. We found that SMI was operationalized and measured using a variety of methods and diagnoses. Most articles focused on a national sample, with the main unit of analysis being at the NH resident-level and based on analysis of secondary data sets. Understanding current evidence about the use of NHs by older adults with SMI is important to policy and practice, especially as we continue to grapple as a nation with how to provide quality care for older adults with SMI.

Keywords

long-term care, health services research, scoping review, institutionalization, mental health

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Background

Although the older working-age population (45–64 years) already outnumbers children and adolescents, older adults (65 years and older) in the United States will outnumber their younger birth cohorts by the early 2030s (Mather et al., 2015; Vespa, 2019). An increasing number of adults are aging with serious mental illness (SMI), which warrants attention but is an understudied issue. SMI is used to describe a host of mental, behavioral, or emotional health conditions that result in ‘serious functional impairment, which substantially interferes with or limits one or more major life activities’ (NIMH » *Mental Illness*, 2021). SMI most often includes diagnoses such as schizophrenia and schizoaffective disorders, bipolar disorder, and major depressive disorder (*Living Well with Serious Mental Illness*, n.d.; NIMH » *Mental Illness*, 2021), but often also includes considerations of severity relating to functional impairment that interferes with the ability to fulfill major life activities (NIMH » *Mental Illness*, 2021). The prevalence of SMI among adults 50 years and

older is roughly 3% (NIMH » *Mental Illness*, 2021). More severe mental disorders are associated with premature mortality and abbreviated lifespans, with mortality occurring up to 25-years earlier than the general population (Bersani et al., 2019). This complex burden of aging with both a psychiatric health condition as well as changes to functional, social and cognitive health can be doubly exacerbated by compromised economic and social security in later life, related to the natural manifestation of SMI (Cummins & Kropf, 2011).

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Government programs, particularly the Preadmission Screening and Resident Review (PASRR) program, and key legal decisions, including the 1999 Supreme Court *Olmstead* decision, have mandated that NHs are not an appropriate setting for the care of those with *solely mental illness*, absent other medical conditions or functional impairment that warrants skilled care. The PASRR program, required of all Medicaid-certified nursing facilities, is a screening mechanism meant to assist in identifying the appropriate care setting for individuals with SMI requiring an extra level of care, and the assessment forms, completed by the designated state mental health authority, are stored in alignment with regulatory compliance (O'Connor et al., 2011). However, individuals with SMI continue to receive care in long-term care settings, such as nursing homes (NH). Between 1985 and 2015, the percent of NH residents with a psychiatric diagnosis increased from 11.2% to 31.4% (Fashaw et al., 2020). Existing evidence suggests that individuals admitted to NHs with mental illness tend to be younger, disproportionately Black, Indigenous, or persons of color (Fullerton et al., 2009; Li et al., 2011), are more likely to transition to long-stay (>100 days) status, and are more likely to reside in NH settings that vary in the quality and comprehensiveness of mental health services offered (Grabowski et al., 2009; Li et al., 2011; Linkins et al., 2006; McGarry et al., 2019; O'Connor et al., 2011). Additionally, NHs that serve a high proportion of SMI residents are found to have lower staffing, lower scores for nursing home quality rating (scored 1 to 5), and are more likely to have deficiencies for neglect and abuse (Jester et al., 2020, 2022).

Given the reality of adults with SMI receiving care in NHs, we conducted a scoping review to explore the extent of the literature describing this topic. Our intent was to examine and map the research on NH care for older adults with SMI over a 20-year period (2000–2020) and to contribute to existing research by providing a critical analysis of the literature on NH use and quality of care for people with SMI. Given the policy relevance of this topic relating to the PASRR program enacted as part of OBRA '87, we were also interested in whether or not researchers have used PASRR screening data in their studies during the time period of our search (2000–2020). The following primary and secondary questions guided our approach: *How is serious mental illness operationalized and measured in the nursing home literature (primary), and how has PASRR data been used, if at all, in prior research, and what methodological approaches have been used to describe NH care for adults with SMI and what is the unit of analysis (individual/facility)?*

Methods

Design

We conducted a scoping review to identify and examine the body of literature relating to older adults with SMI and their

use of NHs, and to explore how SMI is operationalized for older adults in post-acute and long-term care settings. Scoping reviews allow for examination of the “extent, range, and characteristics of evidence on a topic of question” of interest, and are useful in trying to identify existing gaps in the literature that could be addressed by further research (Tricco et al., 2018).

We adapted the *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* (PRISMA) flow diagram for our review process, as well as the guidelines for conducting a systematic scoping review outlined by members of the Joanna Briggs Institute (Peters et al., 2015) and following the PRISMA extension for scoping reviews (Tricco et al., 2018). In conducting and reporting the review, we adhered to the following framework (Peters et al., 2015; Tricco et al., 2018), noting that scoping reviews are useful in answering inherently broad questions, and to clarify working definitions or boundaries: (1) identifying the research question/problem and purpose of the study, (2) literature search, (3) study selection and evaluation, (4) data charting/extraction, and (5) summarizing and reporting results.

Search Strategy

The literature search was performed using PubMed, OVID-MEDLINE, PsycINFO, and SCOPUS (Choi et al., 2018). The definition of SMI offered by the Substance Abuse and Mental Health Services Administration (SAMHSA) was used for guidance in identifying search terms (Druss & Bornemann, 2010; Wolkowitz, 2018).¹ SAMHSA includes in their definition schizophrenia and schizoaffective disorders, bipolar disorder, and severe major depression. Given that the search strategy centered on these more common SMIs, we are likely not capturing more expansive SMI diagnoses and as such, they are not included in this review. The search strategy centered on the combination of key words using Boolean logic; a complete list of search terms used across databases is included in [Supplementary Table 1](#). Search parameters were constrained to produce articles from peer-reviewed sources. We performed two searches between December 2020 and January 2021. A third search in SCOPUS was performed in early 2022 as an additional quality check. The first search was specific to the PASRR program and was performed in December 2020 using PubMed. A second, more comprehensive, search returned 1203 articles across PubMed, OVID-MEDLINE, and PsycINFO. After duplicate removal and narrowing our scope to articles published in the year 2000 or after, we were left with 1040 unique articles to review [Figure 1] and an additional 33 from the SCOPUS search.

Population and Setting

The population of interest was limited to adults 18 years and over who were residents in NHs, as identified by the terms “skilled nursing facilities”, “nursing facilities”, or “nursing

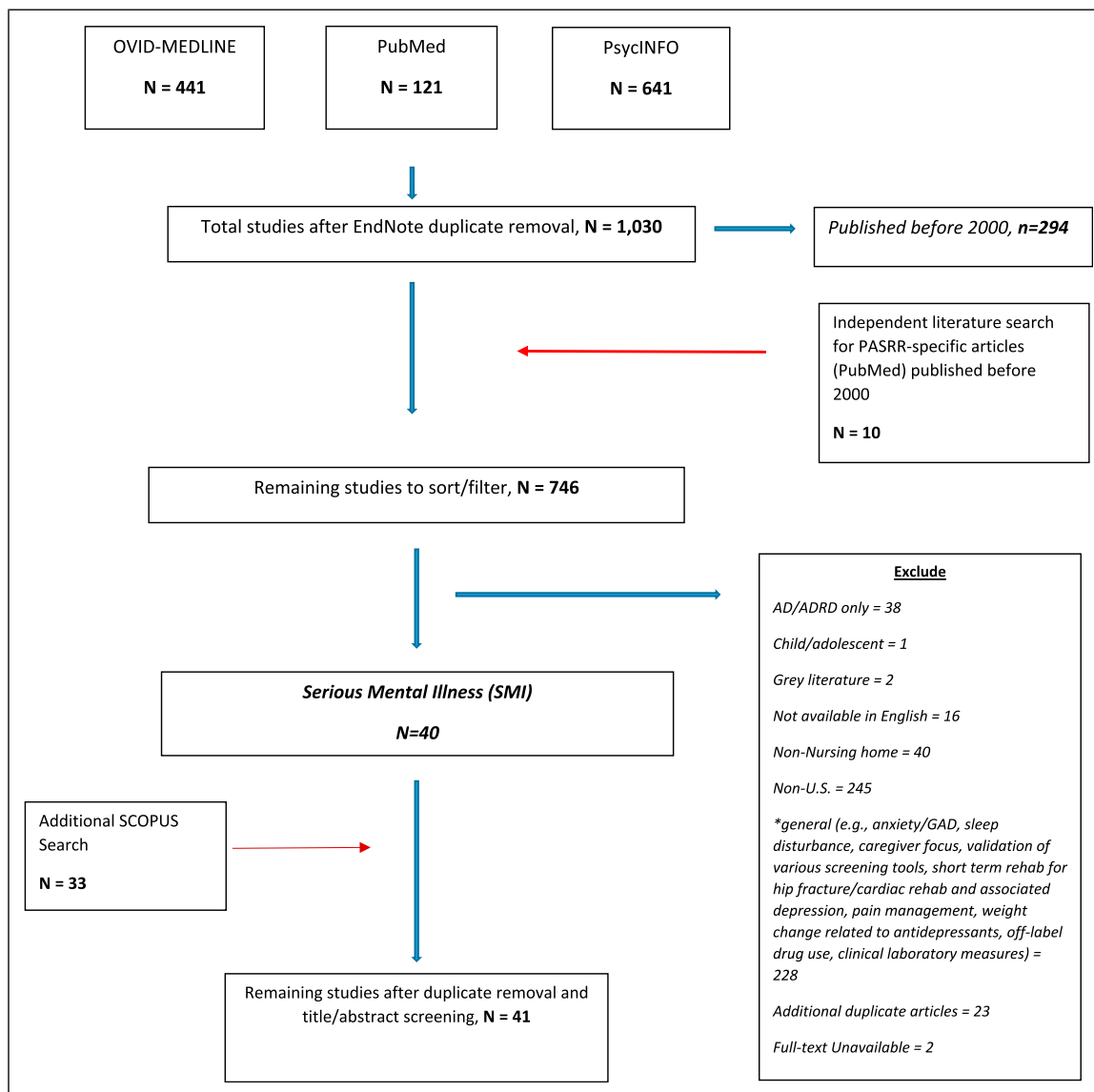


Figure 1. Adapted PRISMA flow diagram describing the different phases of the scoping review process.

homes". The setting of the study or review was limited to a U.S. NH population, given variation in post-acute care and long-term care policy, regulation and payment across countries. While most of the articles that met inclusion criteria predominantly included older adults (65 years and older), we chose to broaden our search parameters to 18 years and older. This was done to account for previous research that has noted the accelerated biological and physical/functional aging of people with SMI, related to premature morbidity and mortality (Druss & Bornemann, 2010; Wolkowitz, 2018).

Selection Process

Two reviewers (TB, KM) performed the process of identification and selection of relevant literature. One reviewer

searched the SCOPUS, PubMed, and OVID-MEDLINE databases, while the second searched PsycINFO, both using the key terms and Boolean operators outlined in [Supplementary Table 1](#). PsycINFO returned the largest number of articles ($N = 641$), followed by OVID-MEDLINE ($N = 441$), PubMed ($N = 121$) and SCOPUS ($N = 33$). We saved search libraries and imported them into EndNote for duplicate removal and sorting. After duplicate removal, $N = 1037$ articles remained.

Reviewers screened titles and abstracts for relevance. To be included, articles had to be published or indexed in early view within the last 20 years (January 2000-January 2021), published in peer-reviewed journals, written and published in English, available in full-text through the [Blinded for Review] library systems, and include adults (18 years or older)

residing in U.S. NHs as the primary study population. Through an iterative process, we further excluded articles that focused only on Alzheimer's disease or dementia without co-occurring serious and persistent mental illness, articles that did not primarily focus on a NH population, or primarily focused on any of the following topics: generalized anxiety, sleep disturbance, caregiver well-being, validation of screening instruments, short-term rehabilitation for physical injury or medical intervention, pain management, antidepressant-associated weight change, off-label drug use, or clinical laboratory measures without concurrent focus on the SMI population. The remaining $N = 166$ articles were sorted and further grouped into categories based on primary population of interest (e.g., bipolar disorder only, depression only, SMI). After title screening and abstract review, we were left with a final sample of 41 articles.

Data Extraction & Synthesis

Articles grouped as focusing explicitly on SMI ($N = 41$) were reviewed in depth, and data abstraction was performed by two authors using a data charting form created through REDCap, a secure web application designed to support data capture for research (*About – REDCap, n.d.*). During full text review, we used the data charting form to identify publication information (first author, year of publication, article title, DOI or PubMed Identifier), research or study design, study objectives, study location, age of population studied, sample size, definition of serious mental illness, study period and data source(s), and major conclusions. Once data abstraction was completed, the survey forms were exported to Excel and cross-referenced for completeness.

Results

Characteristics of the studies reviewed, including study design, study location, age of study population, unit of analysis, study period, sample size, definition of SMI, and whether or not the study design included the use of PASRR data, are presented in [Table 1](#).

Characteristics of Studies Reviewed & Study Population

Most articles reviewed examined a national sample ($n = 26$, 63%) of NH residents. The remaining articles focused on a single state ($n = 7$, 17%) or multiple states ($n = 3$, 7%), with the multiple state studies including a range of 4–47 states. Five (13%) articles were primarily reviews of the current literature, which included topic reviews ([Bartels, 2004](#); [Grabowski et al., 2010](#)), review of federal policies and laws related to mental illness and nursing home care ([O'Connor et al., 2009](#)), and systematic review and/or meta-analysis ([Fornaro et al., 2020](#); [Seitz et al., 2010](#)). While we did not

limit our parameters to a specific age group outside of adults more broadly (18 years and older), studies which provided a sample mean age and standard deviation tended to reflect a population ranging from 33 to 94 years. Seven (18%) studies examined adults residing in or at risk of placement in NHs within the Veterans Health Administration (VHA). The distribution of studies by publication year is depicted in [\[Figure 2\]](#). Article objectives can largely be summarized according to five topical areas. These include trends in the population of adults with SMI residing in NHs after policy actions geared towards diversion from institutional care (e.g., Medicaid exclusion for Institutions of Mental Disease, PASRR program implementation), prevalence or change in prevalence of SMI and comorbid conditions (e.g., dementia) and challenges to providing quality services, clinical and functional service needs, facility and organizational characteristics/practices of NHs that serve people with mental health conditions and quality of care, and clinical correlates of residents with SMI (e.g., potentially avoidable hospitalizations, risk of emergency commitment, pain, substance use disorder, end-of-life and advance directive).

Thirty (73%) of the studies we reviewed were quantitative, five (12%) were qualitative, five (12%) were literature reviews (narrative reviews, systematic reviews and/or meta-analysis), and one (2%) took a mixed methods approach. The main unit of analysis was at the resident-level ($n = 23$), followed by some combination of resident- and facility-level ($n = 7$) or facility-level only ($n = 4$). One additional study sampled NH residents and staff, and an additional study sampled PASRR administrators. Sample size for resident-level articles ranged from 27 ([Madhusoodanan et al., 2014](#)) to 7,364,470 ([Fullerton et al., 2009](#)), for facility-level articles 135 facilities ([Kim et al., 2013](#)) to 8397 facilities ([Rahman et al., 2013](#)), and for facility and resident level articles, 84 resident interviews in 8 NHs ([Molinari et al., 2008](#)) to 2,896,164 residents in 15,096 NHs ([Temkin-Greener et al., 2018](#)) [[Table 1](#)]. The predominant study design was a retrospective analysis of secondary data ($n=29$, 71%), whether that be national survey data (e.g., National Nursing Home Survey) or large-scale datasets (e.g., Minimum Data Set, administrative claims) [[Table 1](#)]. Two studies (5%) took a prospective approach, following administrative claims longitudinally and conducting qualitative interviews and focus groups with nursing home staff, respectively. Four studies (10%) used some combination of primary data collection and secondary data. As mentioned previously, the remaining 13% of articles were literature reviews. Of the 41 total articles we reviewed, only two (5%) used resident-level PASRR Level II screening determinations as a data source for retrospective analyses ([Linkins et al., 2006](#); [Madhusoodanan et al., 2014](#)). While two additional studies included some interaction with PASRR materials, such as medical record review for documentation of screening results ([Molinari et al., 2011](#)) and review of PASRR screening

Table 1. Article characteristics of the final 41 articles meeting inclusion criteria.

Reference (First Author, Year)	Study Design	Methodological Approach	Study Location	Data Source/Study Period	Age Unit of Analysis	Sample Size	Definition of Serious Mental Illness	Identification of Serious Mental Illness Diagnoses	Did this Study Include the Use of PASRR Data?
Eisch, JS (2000)	Outcome evaluation	Qualitative	NY	82.13 y/o (± 10.13) Resident N = 175			Not defined	N/A	No
Mechanic, D (2000)	Retrospective, secondary analysis of national survey data	Quantitative	National sample, U.S.	≥ 18 y/o Resident 1985 NNHS: 5238 1995 NNHS: 8056 1987 MES: 3347 1996 MES: 3747			Schizophrenia and related schizoaffective disorders; Bipolar disorder; Major depressive disorder with psychotic features; Obsessive-compulsive disorder	ICD-9-CM	No
Shea, (2000)	Retrospective analysis using the medicare current beneficiary survey	Quantitative	National sample, U.S.	86 y/o (± 7.3) Resident: 692 Medicare current Beneficiary survey Medicare claims data			Not defined	N/A	No
Buchanan, RJ (2003)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	49.5 y/o (± 16.4) Resident			Schizophrenia and related schizoaffective disorders; Depression	MDS 2.0	No
Bartels, SJ (2004)	Literature summary of evidence-based care models	Narrative review	N/A	Jun 1998–Sept 2000, MDS: 3662 ≥ 18 y/o — —			Schizophrenia, schizoaffective disorder; Bipolar disorder; Treatment-refractory depression	N/A	No
McCarthy, JF (2004)	Retrospective, secondary analysis of cross-sectional resident assessments matched with administrative data	Quantitative	National sample, U.S.	73.6 y/o (± 11.2) Resident 01-Apr-2001, patient assessment instrument (PAI): 9618			Schizophrenia and related schizoaffective disorders; Bipolar disorder and other psychosis	VA patient treatment file ICD-9	No

(continued)

Table 1. (continued)

Reference (First Author, Year)	Study Design	Methodological Approach	Study Location	Data Source	Age Unit of Analysis/Study Period	Sample Size	Definition of Serious Mental Illness	Identification of Serious Mental Illness Diagnoses	Did this Study Include the Use of PASRR Data?
Bowie, CR (2006)	Retrospective analysis of longitudinal secondary data	Quantitative	NY	73.8 y/o (range: 61–88) Resident	May–Nov 2003, longitudinal study of cognitive and functional status: 77		Schizophrenia	DSM-III-R	No
Linkins, KW (2006) ^a	National survey of stakeholders Secondary data analysis Case study	Mixed methods	National sample, U.S. 44 states 4 states (south, west, midwest, northeast)	— — >35 y/o Resident Facility records (2003): 786			Schizophrenia and related psychotic disorders; Bipolar disorder	Medical record abstraction	Yes
Miller, EA (2006)	Prospective analysis of administrative data	Quantitative	National sample, U.S.	≥18 y/o Resident 2001–2003, VHA extended care file & fee basis file: 3,952,229			Not defined	N/A	No
Molinari, V (2008)	Cross-sectional study using retrospective review of secondary national data	Quantitative	National sample, U.S.	67.46 y/o (range: 42–88) Resident 2000–2004, MDS admission forms of male VA nursing home care unit residents: 11,619			Schizophrenia and/or bipolar disorder or comorbid psychiatric conditions	MDS 2.0	No
Molinari, V (2008)	Interviews, survey, focus groups	Qualitative	FL	N/A Facility + resident 8 NFs: 84 interviews Staff training conference: 206 completed questionnaires			Major psychotic disorder; Bipolar disorder; Major affective disorder (i.e., depressive disorders)	Medical record abstraction Medicaid definition of SMI	No
Fullerton, CA (2009)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	80.9 y/o (avg. Age for 2005 admissions) Resident 1999–2005, MDS: 7,364,470 (annual trends) 996,311 (2005 data for demographics, comorbidities, treatment variables)	Focus groups at 2 NFs in tampa bay, FL 80.9 y/o (avg. Age for 2005 admissions)		Schizophrenia or schizoaffective disorders; Bipolar disorder	MDS 2.0	No

(continued)

Table 1. (continued)

Reference (First Author, Year)	Study Design	Methodological Approach	Study Location	Data Source	Age Unit of Analysis	Study Period	Sample Size	Definition of Serious Mental Illness	Identification of Serious Mental Illness Diagnoses	Did this Study Include the Use of PASRR Data?
Walid, MS (2009)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥65 y/o Resident 2004 NNHS: 1,492,200				Not defined Study population including those with 'psychiatric diagnoses,' including schizophrenia, depression, bipolar disorder, anxiety, and obsessive-compulsive disorder	ICD-9	No
Grabowski, D (2009)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	All new NH admissions: 77 y/o (+/- 12) Admission for people with SMI: 62 y/o (+/- 15) Resident 1,150,734 National institute of mental Health's (NIMH's) Collaborative psychiatric Epidemiology surveys (CPES) New admissions were defined as those residents with an admission assessment during calendar year 2005, for whom no MDS record as far back as 1 January 1999 existed in the registry... To track transitions to long-stay status (90 or more days in the facility), we used new admissions from 2004 to ensure complete follow-up				Schizophrenia, bipolar disorder	MDS	No
O'Connor, D (2009)	Literature review/Review of current U.S. policy	Narrative review	N/A	Older adults, ≥ 55 y/o — —				Schizophrenia Delusional disorder Bipolar disorder, and recurrent major depression	Study by bartels et al., 1999: 10.1176/ ps.50.9.1189	No

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Table 1. (continued)

Reference (First Author, Year)	Study Design	Methodological Approach	Study Location	Data Source	Age Unit of Analysis	Sample Size	Definition of Serious Mental Illness	Identification of Serious Mental Illness Diagnoses	Did this Study Include the Use of PASRR Data?
Gammonley, D (2010)	Retrospective analysis of secondary cross-sectional data	Quantitative	National sample, U.S.	≥65 y/o Resident	2003 MDS (residents with mental health history)	Not defined	Authors use CMS definition of mental health history, "those residents admitted to a facility with (a) a schizophrenic, mood, paranoid, panic, or other severe anxiety disorder, somatoform disorder, personality disorder, other psychotic disorder, or another mental disorder that may lead to chronic disability; (b) no primary diagnosis of dementia; (c) a treatment history requiring a level of care greater than outpatient treatment within the prior 2 years; or (d) significant disruption in normal living situation that required law enforcement intervention, residential care, or supportive services occurring within the 2 years prior to admission to the nursing home."	MDS 2.0 CMS definition of mental health history	No
Lemke, SP (2010)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥55 y/o Resident	FY2000 VA administrative files: 27,002	Psychotic conditions and manic disorders	ICD-9-CM VA national patient care database	No	
Lemke, SP (2010)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥18 y/o Resident	Census samples from dept. Of VA nursing homes: (1994) 13,565 (1998) 13,092 (2002) 12,336 (2006) 11,150	Schizophrenia, other psychoses, and bipolar and manic disorders	ICD-9 VA national patient care database	No	

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Table 1. (continued)

Reference (First Author, Year)	Study Design	Methodological Approach	Study Location	Data Source/Study Period	Age Unit of Analysis	Sample Size	Definition of Serious Mental Illness	Identification of Serious Mental Illness Diagnoses	Did this Study Include the Use of PASRR Data?
Seitz, D (2010)	Systematic review	Systematic review of the literature	N/A	74 articles examining psychiatric disorders and psychological symptoms in LTC	2004 NNHS: 13,507		Not defined Defined psychiatric disorders as: dementia, behavioral and psychological symptoms of dementia (BPSD), major depression, depressive symptoms, bipolar disorder, anxiety disorders, schizophrenia, and alcohol use disorders	N/A for literature review 2004 NNHS: ICD codes	No
Frahm, K (2010)	Retrospective analysis of cross-sectional secondary data	Quantitative	National sample, U.S.	65–101 y/o Facility 2003 MDS and OSCAR: 2499 facilities			Schizophrenia or schizoaffective disorders; Bipolar disorder; Depression or manic depression Anxiety disorder	MDS	No
Grabowski, D (2010)	Literature review	Narrative review	N/A	All ages National nursing home survey, national nursing home survey follow-up, national medical expenditure survey Claims data, medicaid and medicare Studies included were conducted between 1980 and 2008			Schizophrenia, bipolar disorder, other psychotic disorders	DSM-IV	No
Aschbrenner, KA (2011)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥18 y/o Resident 2008, MDS new admissions: 286,411			Schizophrenia or schizoaffective disorders; Bipolar disorder; Depression	MDS 2.0	No
Aschbrenner, KA (2011)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥18 y/o Resident 2005, MDS new admissions: 1,094,560			Schizophrenia; Bipolar disorder	MDS 2.0	No
Cai, X (2011)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	80.4 y/o (+/- 0.2) Resident 2004 NNHS: 13,507 residents in 1174 NFs			Schizophrenia or schizoaffective disorders; Bipolar disorder; Other psychosis	ICD-9-CM	No
Li, Y (2011)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥18 y/o Resident + facility 2007 MDS new admissions and OSCAR: 1,314,814 new admissions to 15,386 nursing homes			Schizophrenia or schizoaffective disorders; Bipolar disorder	MDS	No

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Table 1. (continued)

Reference (First Author, Year)	Study Design	Methodological Approach	Study Location	Data Source	Age Unit of Analysis	Sample Size	Definition of Serious Mental Illness	Identification of Serious Mental Illness Diagnoses	Did this Study Include the Use of PASRR Data?
Simon, SE (2011)	Retrospective analysis of secondary data	Quantitative	All U.S. states, excluding NC, NV, and AZ due to incomplete data	22–64 y/o Resident 2002 MAX long-term care file, medicaid claims: 134,420			Not defined Mental disorders defined by ICD-9-cm codes 295–302 and 306–314 (exclude dementia and related conditions, substance use disorder, mental retardation per PASRR requirements)	ICD-9-CM PASRR requirements	No
Molinari, V (2011)	Chart reviews for residents at NHs Focus groups for staff members	Qualitative	FL	35–100 y/o Resident + staff 73 residents' charts 40 staff members in the focus groups			Not defined	N/A	No
O'Connor, D (2011)	Review of PASRR documents from states included in the study Key informant interviews	Qualitative	Ca, CO, CT, FL, in, MI, NV, OH, OK, PA, VA, WA, WI	Age not specified PASRR professionals: 18 September 2009–December 2009			Schizophrenia, bipolar disorder, psychoses	N/A	No
Becker, MA (2012)	Retrospective cohort study	Quantitative	FL	80.2 y/o (+/- 13.4) Resident + facility 31-Dec-2002 to 30-Jun-2005, medicaid FFS claim data & OSCAR: Medicaid-certified NFs = 584 Medicaid enrolled residents 32,604			Major psychotic disorder (schizophrenia, delusional disorder, shared psychotic disorder, brief psychotic disorder, psychotic disorder NOS) Bipolar disorder Major affective disorder Schizophrenia or schizoaffective disorders; Bipolar disorder; And other psychotic disorders	ICD-9-CM	No
Bowersox, NW (2013)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥18 y/o Resident + facility FY1999-FY2007, MDS and VHA national patient care database: Sample size reported for select years – 15,234 (FY99) 13,347 (FY02) 13,570 (FY04) 14,323 (FY07)			Bipolar disorder Major affective disorder Schizophrenia or schizoaffective disorders; Bipolar disorder; And other psychotic disorders	MDS VHA national patient care database	No

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Table 1. (continued)

Reference (First Author, Year)	Study Design	Methodological Approach	Study Location	Data Source	Age Unit of Analysis	Study Period: Sample Size	Definition of Serious Mental Illness	Identification of Serious Mental Illness Diagnoses	Did this Study Include the Use of PASRR Data?
Kim, HM (2013)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	N/A Facility		FY 2005–2007, VHA administrative records + MDS: 135 NFs	Schizophrenia or schizoaffective disorders; Bipolar disorder And other psychosis	MDS 2.0 VA NPCD ICD-9-CM	No
Rahman, M (2013)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	N/A Facility		2000–2008, MDS + OSCAR + AHA data + medicare enrollment/claims: 7,861-8,397	Schizophrenia or schizoaffective disorders; Bipolar disorder	MDS	No
Street, D (2013)	Policy review and primary data collection (qualitative interviews)	Qualitative	National sample, U.S.	N/A Facility		2005 (updated 2010, 2012) state nursing home regulations	Schizophrenia, bipolar disorder, and depression	Literature	No
Brennan, PL (2014)	Cross-sectional, retrospective analysis of secondary data	Quantitative	National sample, U.S.	81 y/o (+/- 13) Resident		2004 NINHS: 13,507	Manic disorder, single episode Bipolar affective disorder, manic Bipolar affective disorder, unspecified Manic-depressive psychosis, other and unspecified Schizophrenic disorders Paranoid states Nonorganic psychoses, excluding depressive type psychosis	ICD-9-CM	No
Madhusoodanan, S (2014)	Retrospective review	Quantitative	NY	Not reported Resident		Jan-Mar 2013, PASRR forms and chart review: 27	No specific diagnoses provided, just 'serious mental illness'	PASRR level II determination	Yes
Barry, LS (2018)	Retrospective analysis of secondary data	Quantitative	CT	27–92 y/o Resident		May 2013–2015, MDS admission and quarterly assessments, medical record review, utilization review data: 86	Schizophrenia; Bipolar disorder	MDS 3.0	No

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Table 1. (continued)

Reference (First Author, Year)	Study Design	Methodological Approach	Study Location	Data Source/Study Period	Age Unit of Analysis	Sample Size	Definition of Serious Mental Illness	Identification of Serious Mental Illness Diagnoses	Did this Study Include the Use of PASRR Data?
Gen, X (2018)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥65 y/o Resident 2015 MDS (cross-sectional, first NH assessment), nursing home compare, long-term care focus data set: 3,270,713			Schizophrenia/psychosis Bipolar disorder	MDS	No
Temkin-Greener, H (2018)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥65 y/o Resident + facility 2011-2014 MDS; 2,896,164 new post-acute admissions			Schizophrenia/psychosis Bipolar disorder	MDS ICD-9 codes	No
McGarry, BE (2019)	Instrumental variable study, retrospective secondary data	Quantitative	National sample, U.S.	≥18 y/o Resident + facility 2005-2010 MDS v2.0, MedPAR, OSCAR, 2010 U.S. Census, 2010-2015 ACS; FFS medicare beneficiaries newly admitted to NH between 2006-2010 with SMI diagnosis—58,571 residents in 12,027 unique facilities			Schizophrenia Bipolar disorder	MDS v2.0	No
Temkin-Greener, H (2019)	Retrospective analysis of secondary data	Quantitative	National sample, U.S.	≥65 y/o Resident + facility 2014-2015, MDS, MedPAR, medicare beneficiary summary, nursing home compare: 807,630 residents in 15,234 NHs			Schizophrenia/psychosis Bipolar disorder	MDS ICD-9 codes	No
Fornaro, M (2020)	Systematic review and meta-analysis	Systematic review, meta-analysis	N/A	Electronic database searches from 1980 to Jul-2017 To determine the prevalence and correlates of major depressive disorder, bipolar disorder, and schizophrenia spectrum disorder in NH residents without dementia. Identified 32 observational studies			Major depressive disorder Schizoaffective disorder or schizophrenia Bipolar disorder	DSM ICD codes	No

ACS: American Community Survey; AHA: American Hospital Association; FFS: fee-for-service; NNHS: National Nursing Home Survey; MAX: Medicaid Analytic Extract Data; MedPAR: Medicare Provider and Analysis Review; MES: Medical Expenditure Survey; MDS: Minimum Data Set; OSCAR: Online Survey, Certification, and Reporting; NPCD: National Patient Care Database; VHA: Veterans Health Administration
^aTable provides description of all study components. Study did not identify names of individual states.

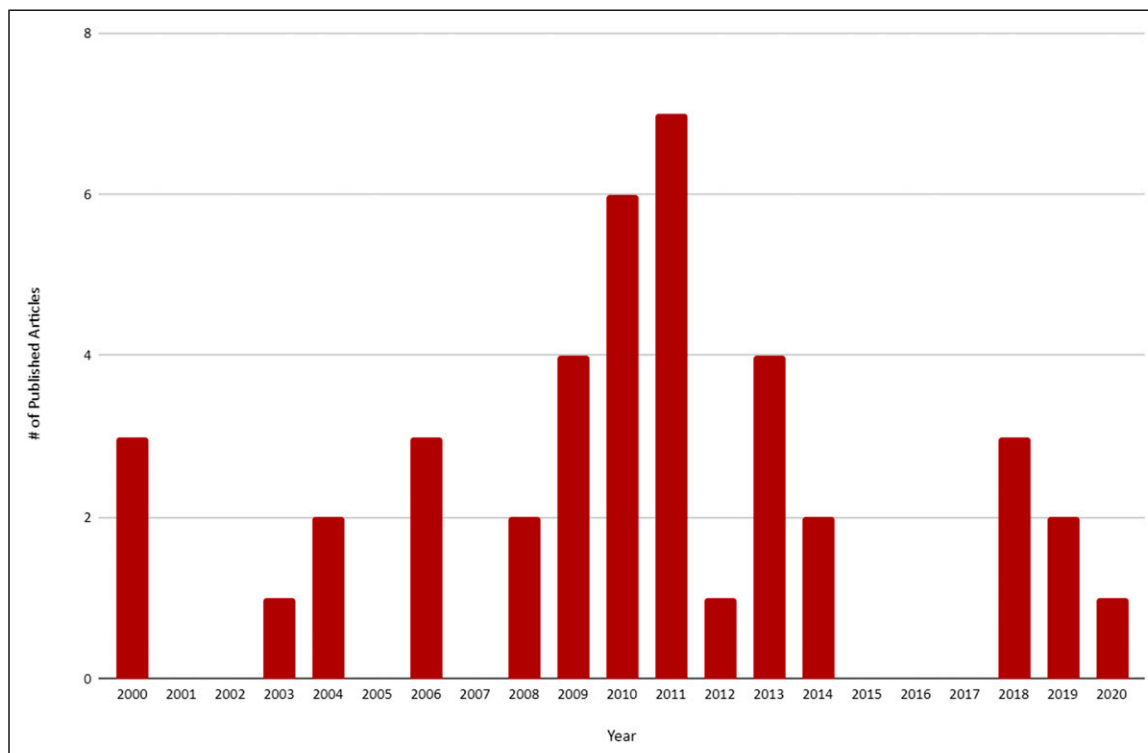


Figure 2. Number of peer-reviewed publications by year ($N = 41$).

tools (O'Connor et al., 2011), their analyses did not incorporate PASRR data.

Definition of Serious Mental Illness

Nine studies (23%) did not offer explicit definitions of SMI. Of these nine studies, four provided population parameters that included specific mental health disorders but did not refer to these groupings as encompassing SMI. Walid and Zaytseva (2009) operationalized their study population as including those with ‘psychiatric diagnoses,’ specifically schizophrenia, depression, bipolar disorder, anxiety, and obsessive-compulsive disorder. Gammonley et al. (2010) offered the Centers for Medicare & Medicaid Services (CMS) definition of ‘mental health history’ to operationalize SMI, which includes one of the following: those admitted to a NH with a “schizophrenic, mood, paranoid, panic, or other severe anxiety disorder, somatoform disorder, personality disorder, other psychotic disorder, or another mental disorder that may lead to chronic disability” but no primary dementia diagnosis, an individual who has required more than outpatient care in the previous 2 years, or a disruption to a living situation requiring law enforcement involvement, residential care, or supportive services in the 2 years preceding NH admission. Seitz et al. (2010) operationalized SMI using a list of psychiatric disorders including dementia, behavioral and psychological symptoms of dementia, major depression, depressive symptoms, bipolar disorder, anxiety disorders,

schizophrenia, and alcohol use disorders, but did not explicitly state or indicate these as operationalizing SMI. Lastly, Simon et al. (2011), operationalized SMI using ICD-9-CM codes (295-302 and 306-314; e.g., schizophrenia and schizoaffective disorders, episodic mood disorders, delusional disorders, other nonorganic psychoses, pervasive developmental disorders, anxiety, personality disorders, depression, neurotic disorders and other nonpsychotic mental disorders), excluding ADRD, substance use disorder, and intellectual disability/developmental disability per PASRR legislation.

Of the common SMIs included in the search, the most common operationalized definition included bipolar disorder and/or schizophrenia or schizoaffective disorders, appearing in 21 (51%) and 21 (51%) article definitions, respectively. Depression was included as sufficient to indicate SMI in 7 (17%) of the articles we reviewed, but was inconsistently operationalized with no single diagnostic description used consistently. Variations in how depression was operationalized include major depressive disorder with psychotic features, recurrent major depression, treatment refractory depression, depression or manic depression, and ‘depression,’ broadly defined. Anxiety and obsessive compulsive disorder were both included in one article. Additional terms used to indicate classification as a SMI included: comorbid psychiatric conditions, major affective disorder (i.e., mood disorder, including major depressive disorder and bipolar disorder), major psychotic disorders (schizophrenia,

delusional disorder, shared psychotic disorder, brief psychotic disorder, psychotic disorder - not otherwise specified, NOS), delusional disorder, psychotic conditions and manic disorders, other psychotic disorders, other psychoses, and/or psychoses.

A variety of approaches were used to document/classify resident or participant diagnosis with SMI, or to classify and group mental health diagnoses as SMI, with sometimes single diagnoses used as sufficient to indicate SMI. Thirty (73%) studies used a single approach to identify and/or group diagnoses as SMI. This included ICD-9-CM or ICD-10-CM codes ($n = 7$, 17%), the Minimum Data Set v2.0 or v3.0 ($n = 13$, 32%), medical record abstraction ($n = 1$, 2%), existing literature ($n = 2$, 5%) or the DSM ($n = 2$, 5%), and PASRR Level II assessment ($n = 1$, 2%). Ten (24%) studies used some combination of the above sources, as well as some combination of VA patient care files, the VA National Patient Care Database, and/or the Medicaid or CMS definition of mental health history. Five (12%) studies did not describe an approach for how they identified or classified SMI, operationalizing SMI without explanation of specific diagnoses; 40% were qualitative and 60% were quantitative.

Major Conclusions & Study Themes

After summarizing and reviewing the main conclusions from all of the identified studies, six main themes emerged. First, studies focused on the demographic characteristics of people with SMI (e.g., age, gender, and race/ethnicity) and the impact on their NH placement and care. Second, studies included recommendations for how to improve care for people with SMI in NHs, such as improvements in training for staff, the need for further/future research, opportunities for policy change, and the idea of more community options. Third, some studies discussed how PASRR impacts care for NH residents with SMI and issues that the process presents. Fourth, differential care for people with SMI versus residents without SMI, including topics such as limited access to mental health services, differences in medication and/or pain management, and general differences in care. The fifth theme was related to the increased prevalence of SMI in NHs, including the idea that a significant number of these residents could likely live in the community if proper supportive services were available. Finally, the sixth theme that arose in a handful of the identified studies regarded the quality of NHs and quality of care that residents with SMI receive. Specifically, the literature has demonstrated that having SMI leads to both placement in lower rated NHs and lower quality of care within NHs.

Discussion

This scoping review aimed to characterize the status of the literature describing adult NH resident populations with SMI, as well as how SMI is operationalized and measured. Given

the federal policy relevance of this topic, specifically relating to the PASRR program enacted as part of OBRA '87, we were also interested in whether or not researchers have used PASRR screening data in their studies during the time period of our search (2000–2020). The peak publication years center around 2010 and 2011, with a 4-year gap between 2014 and 2018.

First, we found that SMI was operationalized and measured using a variety of methods, including existing literature or federal guidelines/definitions, administrative data, or diagnostic tests or codes. Different conditions were used to define SMI as well. Of the common SMIs included in the search and subsequent review, the most common operationalized definition of these SMIs included bipolar disorder and/or schizophrenia or schizoaffective disorders, either as the sole descriptor or in combination with other diagnoses. Data limitations likely contribute to the variation in how SMI is operationalized when using secondary data; if resident level data is unavailable, the emphasis shifts towards diagnoses available at the facility level. In general, SMI was inconsistently operationalized across publications; however, study conclusions generally centered on the same topics. Topics included: (1) complex mental health conditions presenting challenges to NH staff, (2) the need for staff training on the management of mental illness and related behavioral presentations, (3) difficulty placing people with SMI in NHs post-hospital encounters as well as the increased likelihood of people with SMI ending up in low quality NHs, (4) limited access to and variable quality of NHs that provide mental health services beyond medication management and psychiatric consultation, and (5) a reorientation towards prevention and management, including integrated care and supportive housing policies, for adults with SMI to prevent NH placement in the long-term.

Second, we aimed to understand what methodological approaches have been used to describe NH care for adults with SMI, their unit of analysis, and use of PASRR data, if any. Most articles (63%) focused on a national sample, with the main unit of analysis being at the NH resident-level based on a retrospective review of secondary administrative or survey data. Despite the roughly 30 years since the start of the federal PASRR program requirement, we identified only two studies (Linkins et al., 2006; Madhusoodanan et al., 2014) that used PASRR screening data in their analyses. Two additional studies (Molinari et al., 2011; O'Connor et al., 2011) reviewed resident medical records for PASRR screening results and reviewed PASRR screening tools more broadly. This finding calls into question the accessibility of PASRR screening data for use in research and evaluation, as well as the best method for identifying NH residents with positive PASRR level II screening for SMI, given variability in state specific screening processes. For example, the PASRR Technical Assistance Center (PTAC) national annual report compares NH residents with a PASRR-identified SMI in the MDS versus those with a recorded diagnosis of SMI without

PASRR identification, where the MDS identifies a larger proportion of SMI diagnoses than PASRR state data (PASRR Technical Assistance Center, 2019). With all the federal and state investment in PASRR, we need to see more initiatives on the federal and state levels to make PASRR data accessible to caregivers, as well as researchers.

Researchers studying NH care used by people with SMI need to be mindful of variable definitions of SMI and possible bias to the results given lack of consistent definition. For example, given that PTAC found that a narrow definition excludes a large portion of the population, there is a strong potential of the under-estimate of SMI in current sources. The data that are typically used to operationalize SMI do not account for the previous history of SMI, taking medication for SMI, or trajectories of care due to SMI using a life course perspective. Hence, our suggestion would be that to adequately capture the prevalence of SMI for NH residents, a combination of PASRR assessment data and MDS (and possibly Medicaid and Medicare claims data) are needed to correctly identify the proportion of residents with SMI in NHs.

Future Research Directions

This review summarized current studies operationalizing SMI for NH residents and measuring outcomes for residents with SMI. Most of these studies used observational data with limited availability of precision in measuring SMI. Hence, there are substantial concerns in generalizability of results that use different definitions and methods. This body of literature could benefit from the use of mixed methods and opportunities for triangulation across data sources and modes of data collection, given the complexity of the topic. An example would include using administrative data to measure SMI and track outcomes of care for residents with SMI as well as interviewing residents with SMI being discharged from hospitals to NHs about how their diagnoses were assessed, whether they were captured in PASRR and whether they received any other types of care supports in the NHs. Similarly, it would be helpful to understand the perspectives of hospital discharge planners who work with varying sources of data on SMI diagnoses, how decisions are made about referrals and additional SMI screening to meet OBRA requirements.

This literature also needs to give more attention to the intersectionality of race/ethnicity and gender to assess equity considerations in how SMI is diagnosed/tracked and how subsequent care is delivered. Future research should continue to center the SMI population and consider intersecting identities of age, sex, and race to better understand differences in care and the impact of PASRR.

Strengths & Limitations

As with other reviews, we had to set specific parameters for inclusion listed above, which make it difficult to capture all studies on the topic. Specifically, we did not include the terms

severe mental illness or *severe and/or serious and persistent mental illness*. This decision was due in part to our reference definition of serious mental illness, as defined and referred to by SAMHSA and outlined in the federal PASRR legislation (*Living Well with Serious Mental Illness*, n.d.; *Medicaid Program; Preadmission Screening and Resident Review*, 2020). Given that the search strategy centered on these more common SMIs, we are likely not capturing more expansive SMI diagnoses and as such, they were not included in this review. Additionally, our search parameters only cover the last 20 years of research published in peer reviewed academic journals.

Strengths of this study were that it took into consideration a wide scope of the topic and our use of an interdisciplinary team gave us multiple perspectives in helping to operationalize the terms and reach consensus. To our knowledge, this is the first such review on this topic of growing policy relevance. This review highlights methodological and substantive findings related to care of adults with SMI in nursing homes over the last 20 years. Our findings about the variability and lack of uniformity in how SMI is operationalized within the different NH populations contributes to difficulty in defining and tracking this group across care transitions or within existing datasets. These findings are important in light of the growing reports of increasing use of NHs by younger and older adults with serious mental illness and growing racial/ethnic disparity in use (Fashaw-Walters et al., 2021; Nelson & Bowblis, 2017).

Conclusion and Clinical Implications

Understanding current evidence about the use of NHs by older adults with SMI is important to policy and practice, especially as we struggle as a nation in how to provide quality care for older adults with SMI. Future work needs to include PASRR data in measuring SMI, and tracking outcomes for NH residents with SMI to increase validity and generalizability of findings, as well as include primary data collection and mixed methods designs to triangulate across data sources. The growing proportion of adults with SMI in U.S. NHs is relevant to clinical practice, specifically the provision of mental and behavioral health care to individuals with multiple comorbid conditions living in congregate care settings. Additionally, clinical partnerships between long-term care providers and mental/behavioral health specialists may help to improve care coordination and care quality of aging adults with SMI.

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Supplementary Material

Supplementary material for this article is available online.

Note

1. <https://www.samhsa.gov/serious-mental-illness>

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