Title

Secondary Analysis of Existing Datasets for Dementia and Palliative Care Research: High-Value Applications and Key Considerations.

Journal

Journal of palliative medicine, 21(2)

ISSN

1096-6218

Authors

Hunt, Lauren J
Lee, See J
Harrison, Krista L
et al.

Publication Date

2018-02-01

DOI

10.1089/jpm.2017.0309

Peer reviewed

JOURNAL OF PALLIATIVE MEDICINE
Volume 21, Number 2, 2018

DOI: 10.1089/jpm.2017.0309

Special Report

Secondary Analysis of Existing Datasets for Dementia and Palliative Care Research: High-Value Applications and Key Considerations

Lauren J. Hunt, MSN,[1,2] See J. Lee, MD,[2,3] Krista L. Harrison, PhD,[2,3] and Alexander K. Smith, MD, MS, MPH[2,3]

Abstract

Objective: To provide a guide to researchers selecting a dataset pertinent to the study of palliative care for people with dementia and to aid readers who seek to critically evaluate a secondary analysis study in this domain.
Background: The impact of dementia at end-of-life is large and growing. Secondary dataset analysis can play a critical role in advancing research on palliative care for people with dementia.
Methods: We conducted a broad search of a variety of resources to: 1. identity datasets that include information germane to dementia and palliative care research; 2. review relevant applications of secondary dataset analysis in the published literature; and 3. explore potential validity and reliability concerns.
Results: We synthesize findings regarding: 1. Methodological approaches for determining the presence of dementia; 2. Inclusion and measurement of key palliative care items as they relate to people with dementia; and 3. Sampling and study design issues, including the role and implications of proxy-respondents. We describe and compare a selection of high-value existing datasets relevant to palliative care and dementia research.
Discussion: While secondary analysis of existing datasets requires consideration of key limitations, it can be a powerful tool for efficiently enhancing knowledge of palliative care needs among people with dementia.

Keywords: dementia; palliative care; secondary dataset analysis

Introduction

The impact of dementia at end of life is large and growing.[1] Alzheimer's disease was the fifth leading cause of death among people over the age of 65 in 2014 in the United States[2] and it is estimated that 40%–50% of all decedents over the age of 65 die with or from some form of dementia.[3,4] With the expected tripling of the United States dementia population to 13 million people by 2050, dementia at end of life will remain a major public health concern.[5]

People with dementia have a high burden of symptoms and other palliative care needs. Rates of pain and dyspnea are similar to rates in other serious illness.[6,7] Potentially burdensome transitions to the hospital and invasive procedures of questionable benefit—such as enteral feeding and intubation—are common in the last six months of life.[8] Worldwide, experts agree that a palliative care approach, which emphasizes symptom management and enhancing quality of life beginning at the onset of life-limiting illness through till death and bereavement, is ideally suited to people with dementia at all stages and across etiologies.[9,10]

There is an urgent need to develop evidence-based palliative treatments tailored to people with dementia. Secondary dataset research can be an efficient and effective means for increasing knowledge to inform clinical and policy interventions and practices in this domain. Secondary dataset research refers to the analysis of data that were collected for another purpose (Table 1).[11] Potential applications include elucidating the epidemiology of symptoms, assessing caregiver burden, and describing trajectories of function for people with dementia.[12] However, there are limitations to secondary dataset analysis that require consideration.[13]

The goals of this article are twofold. Our first goal is to help researchers select the best dataset to answer questions pertinent to the study of palliative care for people with dementia. Our second goal is to aid readers who seek to critically evaluate a secondary analysis study of palliative care and dementia. We address three main topics that are critical to these goals: (1) Methodological approaches for determining the presence of dementia; (2) Inclusion and measurement of key palliative care items as they relate to people with dementia; and (3) Sampling and study design issues, including

[1]Department of Physiological Nursing, University of California, San Francisco, San Francisco, California.
[2]San Francisco Veterans Affairs Medical Center, San Francisco, California.
[3]Division of Geriatrics, Department of Medicine, University of California, San Francisco, San Francisco, California.
Accepted November 27, 2012.

Table 1. Sources of Existing Data for Secondary Analysis Studies of Palliative Care for People with Dementia

Data sources	*Description*
Administrative data	Data generated from reimbursement claims use to bill for clinical encounters, often based on International Classification of Disease codes or discharge diagnoses, (e.g., Medicare administrative claims available through ResDac).
Medical records	Electronic or paper records of patient's medical information, including medical history, care or treatments received, test results, diagnoses, and medications taken.
Standardized residential or home care clinical assessments	Data collected as part of a mandated process for clinical assessment of long-term care residents, for example, the Long Term Care Facility Minimum Dataset or the Outcome and Assessment Information Set.
National health surveys	Surveys undertaken by a governmental agency to monitor and assess the health of the population, generally through series of cross-sectional studies. May be surveys of individuals (e.g., the National Health Interview Survey) or providers (e.g., the National Ambulatory Medical Care Survey).
Nationally representative panel studies	A longitudinal survey in which data are collected on the same panel of subjects over time. As one panel is at the middle or end of its participation, a panel of new participants is enrolled (e.g., Health and Retirement Study; National Health and Aging Trends Study).
Other primary research studies	Research studies initiated by a primary investigator(s). These studies may be observational (retrospective, cross-sectional, case–control, or longitudinal) or experimental.

the role and implications of proxy-respondents. We highlight several high-value datasets that could be used for studies of palliative care and dementia. Finally, we discuss and synthesize key considerations and limitations of secondary dataset analysis for dementia and palliative care research.

Methods

We conducted a broad search of a variety of resources with the following objectives: (1) identify datasets that include information germane to dementia and palliative care research; (2) review relevant applications of secondary dataset analysis in the published literature; and (3) explore potential validity and reliability concerns of secondary dataset analysis in this domain. To identify datasets, we explored several dataset compendia, including the National Archive of Computerized Data on Aging (www.icpsr.umich.edu/icpsrweb/NACDA/), Society of General Internal Medicine Dataset Compendium (www.sgim.org/communities/research/dataset-compendium), and the University of California, San Francisco's Clinical and Translational Science Institute's large dataset inventory (https://accelerate.ucsf.edu/research/celdac). We reviewed the websites and documentation of potentially relevant studies. We searched PubMed for examples of applications, as well as methodological and validation studies, relevant to secondary dataset analysis within the domain of dementia and palliative care research.

We synthesized findings from this process to address the three topical areas of this article. In addition, we applied findings to develop criteria for identifying exemplars of high-value existing datasets applicable to dementia and palliative care research (Table 2). Criteria included (1) ongoing or recently completed data collection; (2) nationally representative or population-based data; (3) proxy-responses available as applicable; (4) validated method for determining dementia status; (5) assessment of symptoms and end-of-life care preferences, planning, treatments, and quality. Because this table is intended as a guide and resource, rather than the product of a full systematic review, it is not all-inclusive and there are other studies that could potentially meet these criteria.[14]

Results

Determining the presence, type, and severity of dementia

Dementia is characterized by evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains that interferes with independence in everyday activities.[15] Alzheimer's disease comprises about 60%–80% of dementia cases, followed by less common dementia syndromes: Vascular Dementia, Frontotemporal Dementia, Dementia with Lewy Bodies, and Parkinson's Disease with Dementia, or mixed etiology.[3] The intangible nature of dementia, the variety of causes, and the continuum of severity make determination of dementia status complex. Here, we discuss sources of information and approaches for determining dementia status using existing datasets.

Expert panel evaluation. This method entails a full history, clinical exam, and administration of a battery of neuropsychological tests to a study participant. Additional tests may include measures of physical function, collection of biomarkers, and imaging studies. A caregiver/other informant may be interviewed for collateral information. An interdisciplinary panel of two or more experts subsequently reviews medical records and these findings to determine whether a study participant meets current diagnostic criteria for dementia. The Aging, Demographics, and Memory Study (ADAMS) and Framingham Heart Study used this approach, for example (Table 2).

The expert panel evaluation is sometimes referred to as the gold standard for determining dementia status in research studies and is used as the benchmark for assessing the sensitivity and specificity of other methods.[16] This method allows for consideration of a variety of factors that influence

Table 2. High-Value Existing Datasets Applicable to Dementia and Palliative Care Research in the United States

Dataset and website	*Description*	*Dementia/cognitive impairment measures and classification*	*Key palliative care measures*
Health and Retirement Study (HRS)/ Study of Assets and Health Dynamics Among the Oldest Old (AHEAD) http://hrsonline.isr.umich.edu/	Design: Longitudinal panel survey Time period: 1992-ongoing Target population: United States adults age 50+ Sampling methodology: Population-based and purposive sampling (spousal dyads); oversampling of black and Hispanic households and Floridian residents. Sample size: 38,138 Data collection methods and frequency: biennially via telephone and in-person interviews, leave-behind questionnaires, mailed and internet surveys. Proxy availability: available for all years except HRS 1992 and 1994 Linkages: CMS, IRS, Social Security, National Death Index, Veteran's Administration Medical Records, Dartmouth Atlas. Also associated with a number of international sister studies (e.g., English Longitudinal Study of Aging)	Self-respondents: adapted TICS; number series test and verbal fluency (added in 2010); self-rated memory; various other measures of cognitive function and ability measured in various waves.[66] Proxy-respondents: IQCODE; questions about participant's memory, judgment, behavior, and organizational ability. Both: Ever received a diagnosis of a memory-related disease (question added in 1998). Dementia classification: Various approaches described in literature for classifying dementia status.[31,67,68]	Symptoms: Pain severity and effect on function; difficulty breathing; edema; confusion; fatigue; and headaches. Psychosocial: Depression; other social, psychological, spiritual items via written questionnaire every four years. Function/mobility/geriatric syndromes: functional limitations and supports, falls, hip fractures. Caregivers: Information on caregivers available for spousal dyads.[69] Advance care planning and end-of-life care quality: after-death interview includes items on symptoms in last month of life, presence of advance care plans, use of hospice, place of death; perceived quality of end-of-life care.
Aging, Demographics, and Memory Study (ADAMS) http://aging-memory.duhs.duke.edu/ADAMS.html	Design: Sub-study of the HRS with the specific aim of conducting a population-based study of dementia Time period: 2001-ongoing follow-up through HRS Target population: United States adults age 70+ Sampling methodology: Population-based using HRS sample, stratified based on cognitive function. Sample Size: 856 Data collection methods and frequency: Clinical assessment protocol includes three to four hours in-person structured assessment with a subject and an informant at participant's residence. Some participants selected for follow-up in Waves B, C, D (2002–2009). Also followed through HRS. Proxy availability: Yes Linkages: same as HRS	Participant assessment: full battery of neuropsychological tests; neurological testing; collection of vital signs; buccal swab for Apolipoprotein E genotyping. Informant assessment: participant's personal and family medical history; Blessed Dementia Scale; Dementia Severity Rating Scale; Informant Questionnaire. Dementia classification: Expert panel assigns a preliminary diagnosis of demented, cognitive impairment not demented, or normal cognitive function and likely etiology if applicable. Final diagnosis assigned by a geropsychiatrist after review of medical records.	Same as HRS, with additional information available from caregivers: caregiver well-being (abbreviated CESD, caregiving strain, positive aspects of caregiving experience) and out-of-pocket medical expenditures. Also includes Neuropsychiatric Inventory.

(*continued*)

Table 2. (Continued)

Dataset and website	*Description*	*Dementia/cognitive impairment measures and classification*	*Key palliative care measures*
National Health and Aging Trends Study (NHATS) https://nhats.org/	Design: Longitudinal panel survey Time period: 2011-ongoing Target population: United States adults age 65+ Sampling methodology: Population-based; oversampling of older ages, black race. Sample Size: 12,397 Data collection methods and frequency: annually through in-person interviews Proxy availability: Yes Linkages: CMS, Dartmouth Atlas, supplemental study National Study of Caregiving (NSOC)	Self-respondents: cognitive tests include immediate and delayed recall, orientation, clock drawing test; attempt is made to complete cognitive tests if sample person has a proxy-respondent completing the interview. Proxy respondents: AD8 Dementia Screening Interview. Both: Report of doctor's diagnosis of dementia or Alzheimer's disease. Dementia classification: NHATS investigators provide an algorithm for classifying sample persons as probable, possible, or no dementia cases.[16] A more highly specified version of this algorithm was described in Hunt et al.[70]	Symptoms: Pain presence, limitations on activity due to pain, pain location, medications taken for pain, enhanced assessment of pain included in Rounds 3 and 4; breathing problems; weakness; balance problems; proxies report of behavioral symptoms (wandering, getting lost, can be left alone, hallucinations). Psychosocial: PHQ-2, GAD-2; well-being and social network (self-respondents only); participation in religious and other social activities. Function/mobility/geriatric syndromes: Functional limitations and support (most extensive of studies listed), falls; hip fractures; SPPB performed if participant able. Caregivers: Information on caregivers available through NSOC, including type and duration of care activities, health conditions, caregiver strain and depression, supports. Advance care planning and end-of-life care quality: Round 2 (2012) includes a module on end-of-life plans and care administered to a 1/3 subsample; after-death interview asks about care in the last month of life, including symptom management, function, location of death, quality of communication, overall quality of care.
Framingham Heart Study https://framingham heartstudy.org/	Design: Multigenerational, longitudinal cohort study Time period: 1948-ongoing Target population: Adults age 30+ Sampling methodology: Population-based and purposive sample of residents of Framingham, MA Sample Size: Original cohort = 5209; offspring cohort = 5124; offspring spouse = 103; generation three cohort = 4095; diverse cohort = 507 Data collection methods and frequency: Clinic or field assessments every two years include extensive clinical exams and interviews, collection of labs and other biomarkers (Apolipoprotein E, echocardiograms, brain scans) Proxy availability: Yes Linkages: CMS	Surveillance for incident dementia begun in 1975. All participants undergo MMSE and are also asked if they have ever been told by a doctor they have memory problems, a dementia diagnosis, or Alzheimer's disease. If flagged, they undergo further cognitive testing. Dementia classification: Expert panel reviews every case of possible cognitive decline and dementia and assigns a diagnosis of dementia and dementia subtype based on DSM-IV. Also reviews all participant decedents to determine if participant might have had dementia before death.	Symptoms: respiratory symptoms only Psychosocial: Berkman social network questionnaire, leisure time cognitive and physical activities, CESD. Function/mobility/geriatric syndromes: Functional limitations and supports (Katz, Rosow-Breslau, Nagi), observed physical status (chair stands, measured walk), compensatory strategies and assistive devices, falls and fractures. Advance care planning and end-of-life care quality: healthcare preference questionnaire administered to self-respondents who were able to complete in exam 29. Includes questions regarding wishes for medical care at end-of-life, comfort with talking about death, whether healthcare proxy identified, living will, preferences for location of death, and other items.

(*continued*)

Table 2. (Continued)

Dataset and website	*Description*	*Dementia/cognitive impairment measures and classification*	*Key palliative care measures*
Health ABC Study: The Dynamics of Health, Aging, and Body Composition https://healthabc.nia.nih.gov/	Design: Longitudinal cohort Time period: 1997–2014 Target Population: Unites States adults aged 70+ Sampling methodology: Multi-site, population-based; oversampling of black race. Sample size: 3076 Data collection methods and frequency: Yearly clinical examinations; phone calls every six months in-between visits; quarterly phone interviews focused on end-of-life care were conducted for the final three years of study. Proxies availability: Yes for after-death interviews, otherwise limited Linkages: None available	3MS administered every other year until 2011; TICS administered in 2011–2014 quarterly phone interviews; neuropsychological tests administered as part of sub-studies in limited years; brain scan available for years 10, 11, 13; neurological exam available for years 12 and 13; medication for Alzheimer's year 13. Dementia classification: See Hong et al. for example.[71]	Symptoms: Overall pain available only in last three years of study; specific sites of pain (e.g., feet, hands, hip, back, knee) asked about in some years; unusual tiredness and amount of energy (numerical scale) assessed yearly; nausea; constipation; shortness of breath; difficulty concentrating; difficulty swallowing included last three years of study; neuropathy symptoms assessed in year 4, 11, and 13. Psychosocial: CESD, GDS, or two-items from PHQ-9 (2011–2014); most years include questions regarding social support and networks. Function/mobility/geriatric syndromes: Functional limitations and supports, falls, performance-based physical assessment. Advance care planning and end-of-life care quality: Quarterly assessments in final three years of study include questions regarding decision making, treatment preferences (e.g., cardiopulmonary resuscitation, ventilation, dialysis), presence of living will and power of attorney, knowledge and preferences regarding hospice. After-death exit interview asks about care in the last month of life, including symptom management, function, location of death, quality of communication, overall quality of care.

(*continued*)

Table 2. (Continued)

Dataset and website	*Description*	*Dementia/cognitive impairment measures and classification*	*Key palliative care measures*
National Study of Long-Term Care Providers https://cdc.gov/nchs/nsltcp/	Design: Series of cross-sectional surveys Time period: Began in 2012. Replaced the National Nursing Home Survey, National Home and Hospice Care Survey, and the National Survey of Residential Care Facilities Target Population: Paid, regulated long-term care institutional providers in the United States, including residential care facilities, adult day services, home health, nursing homes, and hospices (no individual level data available) Sampling methodology: Population-based (population = institutional providers) Sample size: In 2014, 5035 residential care facilities and 4800 adult day service providers. Data collection methods and frequency: Biennial; data for residential care communities and adult day care centers is obtained through surveys (mail, email, web-based responses). Data on nursing homes, home health agencies, and hospices are obtained from existing administrative data from CMS (primarily Certification and Survey Enhanced Reporting [CASPER]). Proxies availability: N/A Linkages: No	Adult day centers and residential care facilities are asked how many/percentage of people in their center/facility who have a diagnosis of Alzheimer's disease or other dementia. Data for nursing homes, hospices, and home health agencies derived from CASPER.	Advance care planning and end-of-life care quality: Adult day centers and residential care facilities are asked the number of participants receiving hospice; whether information on advance directives is provided to center participants; whether information is maintained on site; and number of participants with an advance directive. Facilities/centers are asked whether they provide, arrange, or refer to hospice
Long-Term Care Facility Minimum Dataset (MDS) https://resdac.org/cms-data/files/mds-3.0/data-documentation	Design: Standardized assessment administered to all skilled nursing facility residents in the United States (short and long stay) Time period: Data collection began in 1998 with MDS 2.0. MDS 3.0 implemented in 2010. Target population: United States skilled nursing facility residents Sampling methodology: N/A Sample size: Users will often request a limited sample for analysis, for example, 5% random sample Data collection methods and frequency: Comprehensive assessment completed upon admission to facility and then annually or if a significant change in a resident's status occurs. Non-comprehensive assessments are completed quarterly and upon discharge Proxies availability: Assessment is combination or resident and staff assessment Linkages: CMS, HRS, NHATS	For MDS 3.0, the Brief Interview for Mental Status is administered if resident is able to respond. Otherwise staff completes Staff Assessment for Mental Status. Cognitive Performance Scale used in MDS 2.0.Staff also indicate whether the resident has an active diagnosis of Alzheimer's disease or other dementia. Dementia classification: See Miller et al.[72] for example.	Symptoms: Pain assessment interview is conducted if resident can be understood, includes questions regarding presence, frequency, and intensity of pain (numeric or verbal scale), effect on function; if unable to complete interview, staff completes an observational pain tool; list of pain medications; shortness of breath and fatigue (as part of PHQ-9); behavioral symptoms, including psychosis, wandering, aggression as assessed by staff. Psychosocial: PHQ-9 administered via resident interview or staff assessment; resident interview or staff assessment of resident activity preferences. Function/mobility/geriatric syndromes: Functional limitations and supports; performance-based physical assessment if able to complete, urinary and bowel incontinence, falls, swallowing disorders, presence and severity of pressure ulcers. Advance care planning and end-of-life care quality: Staff assess whether resident has a six-month life expectancy based on physician's documentation; resident or caregivers are asked about expectations and desire to return to community; staff assessment of whether resident has received hospice care in the last 14 days.

(*continued*)

TABLE 2. (CONTINUED)

Dataset and website	*Description*	*Dementia/cognitive impairment measures and classification*	*Key palliative care measures*
Medicare Claims Datasets https://resdac.org/cms-data/file-family/Medicare-Claims	Design: Administrative data Time period: Available from 1999 Target population: All United States Medicare-eligible beneficiaries (97% of all adults aged 65+ and some younger due to disability) Sampling methodology: N/A Sample size: Users will often request a limited sample for analysis, for example, 5% random sample. Data collection methods and frequency: Collected in course of receiving medical care. Proxies availability: N/A Linkages: HRS, NHATS	ICD-9 codes: AD and related dementia codes include 331.0–331.2; 331.7; 290.0; 290.10–290.13; 290.20; 290.21; 290.3; 290.40–290.43; 294.0; 294.1; 294.8; 797 ICD-10 codes for dementia are included under categories F01.5x (vascular dementia); F02.8x (dementia in other diseases coded elsewhere, for example AD = G30.x) and F03.9x (unspecified dementia). All categories are distinguished by the presence or absence of behavioral symptoms (e.g., F01.51 indicates vascular dementia with behavioral disturbances). Alzheimer's or other dementia may be indicated from a prescription for an associated medication (acetyl-cholinesterase inhibitor or memantine) in Part D files. Dementia classification: See Newcomer et al.[29]; Taylor et al.[30,73]; Willis[74]	Symptoms, psychosocial, function/mobility/geriatric syndromes: Although there are ICD codes to indicate the presence of symptoms, limitations in activity due to disability, depression, anxiety, geriatric syndromes (e.g., swallowing difficulty), we are not aware of any validation studies of using claims to measure these items in the dementia population. Advance care planning and end-of-life care quality: As of 2016, two CPT codes now exist for Advanced Care Planning discussions (99497 and 99498); CPT codes also exist for receipt of palliative care in various settings. Medicare claims are more valid and reliable means for measuring healthcare service use, including Emergency Department visits, hospitalizations, SNF, and hospice, as compared to self-report.[27]

3MS, Modified Mini Status Exam; AD8, Ascertain Dementia Screening Interview; ADAMS, Aging Demographics and Memory Study; CASPER, Certification and Survey Provider Enhanced Reporting; CESD, Center for Epidemiological Studies Depression Scale; CMS, Center for Medicare and Medicaid Services; CPT, Current Procedural Terminology; DSM, Diagnostic and Statistical Manual of Mental Disorders; GDS, Global Deterioration Scale; GAD, Generalized Anxiety Disorder Scale; HRS, Health and Retirement Study; ICD, International Classification of Disease; IQCODE, Informant Questionnaire on Cognitive Decline in the Elderly; IRS, Internal Revenue Service; MDS, Minimum Dataset; MMSE, Mini Mental Status Exam; NHATS, National Health and Aging Trends Study; NSOC, National Study of Caregiving; PHQ, Patient Health Questionnaire; SNF, Skilled Nursing Facility; SPPB, Short Physical Performance Battery; TICS, Telephone Interview for Cognitive Status.

dementia diagnosis, including factors that may influence neuropsychological test performance, such as educational status and primary language.[17] Moreover, this approach allows for evaluation of decline in cognitive and physical function from a previous level, which may only be apparent from a review of the medical record or from detailed informant questionnaires. Finally, this method is robust enough to include determination of dementia subtype and severity.

The main disadvantage is the time- and resource-intensive requirements of this approach. Consequently, the sample size of the existing dataset may be small. Another concern is panel inter-rater reliability. For example, although agreement on the presence of dementia was high in one study with a panel of seven raters, agreement on degree of severity was poor.[18] Lack of consistency in panel methodology and inadequate transparency in reporting on the decision-making process and information presented to panels is another major concern.[19] Of note, diagnostic criteria may be refined over time, potentially leading to inconsistent dementia diagnoses across studies and time periods.[20]

Neuropsychological tests and other clinical measures of cognition/dementia. Measures available in an existing dataset can range from a single brief dementia screening tool, such as the Mini Mental Status Exam (MMSE), to multiple instruments and assessments commonly included in a full neuropsychological and clinical workup for dementia. For example, the ADAMS dataset, in addition to making the expert panel diagnosis available, also includes results from performance-based and caregiver-completed tools, Apolipoprotein E genotype, and others. Box 1 presents examples of various tools, including multi- and single-domain cognitive function assessments administered to self-respondents, and tools completed by clinician and/or caregiver informants that may be found in existing datasets.

Due to ease of administration, existing datasets often include a brief dementia screening tool. There are a number of both self- and informant-respondent brief screening tools that demonstrate excellent sensitivity and specificity for detection of dementia.[21] For example, the MMSE has a sensitivity of 69%–91% and specificity of 87%–99% for detecting dementia.[21] The informant-rated Ascertain Dementia 8-item Informant Questionnaire (AD8) is another instrument with excellent psychometric properties for detecting dementia.[22]

In contrast to the expert panel evaluation, applying cutoffs to standardized tools could potentially decrease subjectivity in dementia ascertainment in existing datasets, which may reduce inconsistencies across studies and time. On the other hand, it may not be possible to determine dementia subtype and severity if relying only on a single brief dementia screening tool. Furthermore, it will not be possible to detect trends in cognitive functioning unless serial assessments are available. Moreover, there may be validity concerns regarding a particular instrument. For example, the MMSE provides a suboptimal measure of the key cognitive domain of executive function,[23] and is subject to both floor and ceiling effects.[24] Finally, in longitudinal studies, practice effects may influence test reliability if alternative test forms are not available across study time points.[25]

Respondent report of a dementia diagnosis. Some datasets may include the response to a yes or no question as to whether the study participant (or a proxy-respondent answering on their behalf) reports ever having received diagnosis of Alzheimer's disease or other dementia from a healthcare provider. Because of the low sensitivity of this

Box 1. Selection of Instruments to Measure Cognitive Function and Dementia Status

Brief multi-domain cognitive screening tools administered to self-respondents
- Mini Mental Status Exam (MMSE)
- Montreal Cognitive Assessment (MoCA)
- Telephone Interview for Cognitive Status (TICS)
- Brief Interview for Mental Status (BIMS)
- Mini-Cog
- Short Portable Mental Status Questionnaire (SPMSQ)
- Modified Mini-Mental State (3MS)
- Saint Louis University Mental Status Exam (SLUMS)
- Clock Drawing Test

Single domain cognitive assessments administered to self-respondents
- California Verbal Learning Test (memory)
- Trail Making Test (visual attention)
- Boston Naming Test (language)
- Three-Dimensional Constructional Praxis Test (constructional praxis)

Brief cognitive status/dementia screening tools administered to lay or clinician informants
- Ascertain Dementia Screening Interview (AD-8)
- Brief Interview for Mental Status Staff Assessment
- Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)

Dementia Severity Rating Scales
- Global Deterioration Scale (GDS)
- Clinical Dementia Rating (CDR)
- Functional Assessment Staging Tool (FAST)
- Dementia Severity Rating Scale (DSRS)
- Blessed Dementia Rating Scale (BDRS)

method,[26] we do not recommend using this information as the sole method for determining dementia status in secondary dataset analysis. However, it may be useful when combined with other sources of information (see section below on combining sources of information).

Provider documentation of dementia diagnosis. A provider's documentation of a dementia diagnosis may be available in the form of International Classification of Disease (ICD) code(s) or may be a descriptive diagnosis included in a clinical problem list, for example. Primarily, the datasets that include this information will be the result of clinical encounters, such as an administrative claims dataset (e.g., Medicare claims datasets) and medical records (Table 2). However, some surveys of healthcare providers may include this information. For example, the National Ambulatory Medical Survey and the National Hospital Ambulatory Medical Survey asks providers to document the presence of Alzheimer's disease or dementia.

The main advantage of this approach for secondary dataset analysis is that it provides access to datasets with very large, nationally or regionally representative, population-based samples. These datasets also contain detailed and highly reliable information on healthcare service use and costs.[27] Because other diagnoses associated with an individual are often included, these datasets can be useful for studying the effect of comorbidities on healthcare service use.[28] Furthermore, because this information usually does not depend on interaction with study participants, it is not subject to some of the risks of bias present in primary research studies, such as recall and nonresponse bias.

The main disadvantage of this approach is the potential for low sensitivity. One study of Medicare claims found that only 31% of individuals known to have a diagnosis of Alzheimer's dementia had at least one Medicare Part A or Part B claim for Alzheimer's disease in a year-long period.[29] For Medicare and other insurance claims, sensitivity can be improved by expanding the period of time over which claims are examined and the types of files used to identify claims. Another study of Medicare claims found that using a broad set of ICD codes, three years of consecutive data, and physician supplier and physician outpatient files increased the correct detection of people known to have Alzheimer's disease to 87%.[30]

Combining sources of information. Researchers conducting secondary dataset analysis studies can combine results from neuropsychological instruments, other clinical measures, and respondent or provider report of dementia diagnosis to improve the accurate detection of people with dementia. For example, the National Health and Aging Trends study (NHATS) developed an algorithm for use by secondary researchers to categorize study participants by dementia status. The algorithm is based on self- or proxy-report of a dementia diagnosis combined with results from tests of cognitive function or proxy-response to the AD8. When compared to an expert panel evaluation, this algorithm resulted in a specificity of 87% and a sensitivity of 65% for a narrow definition of dementia and a specificity of 61% and a sensitivity of 86% when using a broad definition of dementia.[16] Leveraging survey datasets that can be linked to Medicare or other insurance claims is another approach to improving dementia detection. For example, Feng et al.[31] combined results of cognitive function tests from the Health and Retirement Study (HRS) with documentation of a physician's diagnosis of dementia in Medicare claims data to define the dementia cohort for their study.

Dementia specific palliative care related measures

The utility of a dataset for dementia and palliative care research depends on whether palliative care items and instruments relevant to and validated in people with dementia are available. Due to cognitive and language impairments, measures requiring subjective responses—such as assessments of pain and advance care planning preferences—require special consideration for people with dementia. In addition, as compared to people with other terminal conditions such as cancer or heart disease, people with dementia have certain unique or more frequently occurring palliative care concerns, such as the management of behavioral symptoms and geriatric syndromes. Finally, people with dementia often experience a long and protracted period of decline and prognostication poses greater challenges than other terminal conditions.[32,33]

Advance care planning. People with mild dementia may be able to answer questions regarding presence and components of written instructions for end-of-life care and whether goals of care discussions ever occurred with a healthcare provider.[34] Proxy respondents will be necessary for reliable recall in moderate dementia, and certainly for advanced dementia (see discussion on proxy respondents in next section). After-death interviews with proxy respondents can assess whether quality of care at end of life aligned with patient wishes, and should include information on place of death, symptom management, receipt of hospice or palliative care services, and satisfaction with end-of-life care.[35] Although infrequently encountered in existing datasets, after-death assessments specific to people with dementia have been developed, including the Satisfaction with Care at End of Life in Dementia, Symptom Management at the End of Life in Dementia, and Comfort Assessment in Dying with Dementia.[36]

Pain. Although people often do not associate dementia with pain, studies show that the prevalence of pain in people with dementia is comparable to other terminal diagnoses.[6,37] Assessment of pain in people with dementia is more complex than people without dementia, both in clinical care and in data collected for research.[38] Research demonstrates that people with mild to moderate dementia are able to reliably respond to questions regarding pain.[39] Verbal descriptors (e.g., mild, moderate, severe) are more valid and reliable than numerical descriptors (e.g., 0–10 pain scale).[39] For people with severe dementia, it is best to rely on the responses of a proxy-respondent or an observational tool if available.[40] For example, instructions for staff completing the Long-Term Care Facility Minimum Dataset recommend querying a resident regarding pain if they are at least sometimes understood (Table 2). If the resident is never understood, an observational tool should be administered. A number of observational tools for pain assessment are available. Examples include the Pain Assessment in Advanced Dementia, Pain Assessment Checklist for Seniors with Limited Ability Communicate, and the DOLOPLUS-2.[41]

Depression and anxiety. Depression and anxiety are highly prevalent in people with dementia.[42] People with mild to moderate dementia are generally able to complete depression and anxiety questionnaires with adequate reliability and validity.[43] Some instruments have been developed specifically for people with dementia, such as the Cornell Scale for Depression in Dementia.[44] However, it is more common to encounter instruments intended for screening across a broad spectrum of individuals, such as the Patient Health Questionniare-2 and 9 and the Generalized Anxiety Disorder-2 and 9. Of note, the PHQ-2 has a reported sensitivity of 0.78, specificity of 0.71 for individuals with cognitive impairment.[45,46] Lay or clinician informants can also complete these instruments if necessary.[47]

Behavioral symptoms. People with dementia frequently experience behavioral and psychological symptoms such as hallucinations, delusions, aggressive behaviors, and wandering.[42] These symptoms, in addition to being distressing and difficult for caregivers and clinicians to manage, increase the risk of institutionalization, mortality, and other negative outcomes.[48] Several validated instruments for the assessment of behavioral symptoms are available and may be included in a dataset.[49] For example, the ADAMS study includes the Neuropsychiatric Inventory.[50] Any assessment of these symptoms relies on the availability of caregiver or clinician respondents.

Functional status, mobility, and geriatric syndromes. Evidence of the type and number of functional limitations may contribute to approximating dementia severity if that information is not otherwise available in a dataset.[51] Knowledge of the patterns of functional impairment toward the end of life is necessary for understanding supportive care service needs.[52] A number of instruments to measure functional assessment, such as the Katz Activities of Daily Living Scale[53] and the Lawton Brody Instrumental Activities of Daily Living Scale,[54] are available. Most datasets that include older adults will contain a variation of these instruments. Some datasets include objective measures of physical capacity, such as the Short Physical Performance Battery[55] (e.g., NHATS and Health ABC), which are more reliable than self-report of physical capacity, particularly in people with dementia. Geriatric syndromes and events, such as falls and fractures, swallowing disorders, incontinence, and pressure ulcers are highly prevalent among people with dementia.[56] As with other domains, the ability to reliably answer questions regarding function and geriatric syndromes decreases with increased dementia severity, and other informants will be needed at advanced stages.

Caregiver burden and related issues. People with dementia frequently require assistance from family and other unpaid caregivers.[57] Understanding the characteristics of caregivers and the emotional, financial, and physical burdens associated with caregiving is critical for developing policies and interventions that reduce caregiver burden and improve the quality of care for care-recipients.[57] Some existing datasets provide individual-level information on both caregivers and care-recipients (e.g., HRS, ADAMS). A unique resource for caregiving information is the National Survey of Caregiving (NSOC), a companion study to NHATS. By linking data from NHATS with NSOC, Kasper et al. found that a disproportionate amount of all caregiving hours in the United States go toward caring for people with dementia.[57]

Sampling and study design issues

As with all primary and secondary studies, sampling strategy and study design has important implications for the generalizability of study findings to a target population. Here, we discuss some key considerations specific to dementia and palliative care research.

Sampling and data collection procedures. Probability-based sampling methods will result in better external validity and are less prone to selection bias than convenience samples.[58] On the other hand, purposive sampling can provide useful information regarding household and caregiving arrangements (e.g., HRS enrolling of spousal dyads). The geographical scope of an existing dataset—given local and regional differences in palliative care-related practices and attitudes[59]—is another key consideration. Given the historical lack of representativeness of oldest old, women, and racial minorities in clinical research,[60] secondary researchers should examine whether these groups were oversampled in the original study in order to ensure adequate representation, especially because these groups are disproportionately impacted by dementia.[61,62] Another consideration is the mode of data collection. Research indicates that in-person assessments, as opposed to telephone or written assessments, result in better response rates and less missing data for older adults.[63]

The role of proxy-respondents. The availability and inclusion of proxy-respondents is a crucial consideration when undertaking secondary analysis of an existing dataset. In advanced stages of disease, people with dementia are too impaired to complete complex questionnaires. However, excluding participants because of an inability to respond results in selection bias.[64] Allowing a proxy-respondent to answer questions on behalf of a study participant allows for a more representative sample of people with dementia. There are, however, important implications regarding differences in responses by self versus proxies to consider.

Agreement between self- and proxy-respondents varies depending on the domain assessed.[64] Self- and proxy-respondents tend to have better agreement for assessments of functioning, physical health, and cognitive status, and worse agreement for assessments of psychological and emotional well-being.[64] Proxy-respondents tend to report higher levels of functional impairment and lower levels of emotional and psychological well-being compared to self-respondents with cognitive impairment.[64] Higher levels of caregiver stress may also result in more negative assessments by proxy-respondents as compared to self-respondents.[64] Proxy responses may vary depending on relationship of the proxy to the subject and their caregiving role.[65] This is an important consideration in longitudinal studies in which the person providing the proxy response may be different across assessments.

Discussion

In sum, there are a number of key questions secondary researchers should ask in selecting a dataset for dementia and palliative care research. First, is it possible to detect people

with dementia in the dataset with reasonable sensitivity and specificity? Of note, trade-offs between sensitivity and specificity in determining dementia cases (e.g., applying a higher or lower cutoff score on a brief dementia screening tool) will have important implications for applicability of study findings at the population level. Second, are there relevant palliative care measures in the dataset, and have they been validated in people with dementia and/or in proxy respondents? This question also applies to other covariates and outcomes of interest. Third, is the sample representative of the population of interest, taking into account that trade-offs in individual-level detail versus sample size and representativeness may be necessary? Proxy respondents should be included in survey studies to improve representativeness of dementia across the spectrum of severity. Reviewers should follow the same process in evaluating secondary analysis studies.

Ideally—as is the case with all secondary dataset research—the choice of dataset should be driven by research questions and hypotheses defined a priori. In reality, there is often a more iterative process of adapting a research question to a dataset's available measures.[11] However, it is important to avoid ''fishing expeditions'' for statistically significant associations, which can lead to findings deemed clinically relevant that are in fact due to chance alone. A related pitfall to avoid is circular analysis, also called ''double dipping,'' in which the data used for exploratory data analysis and hypothesis development is the same data used for hypothesis confirmation.

There are other important limitations of secondary dataset research. Many primary studies that make data available to secondary researchers fail to provide sufficient information regarding strategies taken to ensure data fidelity (e.g., lack of published reports around personnel training and quality assurance and control procedures). If using electronic medical records or administrative data, secondary researchers must often contend with extensive amounts of missing data and concerns regarding validity and accuracy of data that was not collected for research purposes.

Conclusion

As their numbers grow rapidly in the coming years, understanding the experiences and needs of people with dementia toward the end of life will be increasingly important. A number of high-value existing datasets are available that can be leveraged for dementia and palliative care research in the United States. While it is necessary to consider important limitations of this approach, secondary analysis of existing datasets can be a powerful tool for efficiently enhancing knowledge that can drive improvements to palliative care for people with dementia.

Acknowledgments

This work was supported by the National Institute of Health's National Institute for Nursing Research (F31NR 015170) and the National Institute on Aging (3R01AG047897-02S1 and T32-AG000212).

Author Disclosure Statement

No competing financial interests exist.

References

1. Taylor CA, Greenlund SF, McGuire LC, et al.: Deaths from Alzheimer's disease—United States, 1999–2014. MMWR Morb Mortal Wkly Rep 2017;66:521–526.
2. National Center for Health Statistics: *Health, United States, 2014: With Special Features on Adults Aged 55–64*. Hyattsville, MD: National Center for Health Statistics, 2015.
3. Alzheimer's Association: 2015 Alzheimer's disease facts and figures. Alzheimers Dement 2015;11:332–384.
4. Byhoff E, Harris JA, Langa KM, et al.: Racial and ethnic differences in end-of-life medicare expenditures. J Am Geriatr Soc 2016;64:1789–1797.
5. Hebert LE, Weuve J, Scherr PA, et al.: Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. Neurology 2013;80:1778–1783.
6. Mitchell SL, Teno JM, Kiely DK, et al.: The clinical course of advanced dementia. N Engl J Med 2009;361:1529–1538.
7. Murray TM, Sachs GA, Stocking C, et al.: The symptom experience of community-dwelling persons with dementia: Self and caregiver report and comparison with standardized symptom assessment measures. Am J Geriatr Psychiatry 2012;20:298–305.
8. Gozalo P, Teno JM, Mitchell SL, et al.: End-of-life transitions among nursing home residents with cognitive issues. N Engl J Med 2011;365:1212–1221.
9. van der Steen JT, Radbruch L, Hertogh CM, et al.: White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. Palliat Med 2014; 28:197–209.
10. Boersma I, Miyasaki J, Kutner J, et al.: Palliative care and neurology: Time for a paradigm shift. Neurology 2014;83: 561–567.
11. Smith AK, Ayanian JZ, Covinsky KE, et al.: Conducting high-value secondary dataset analysis: An introductory guide and resources. J Gen Intern Med 2011;26:920–929.
12. Kelley AS, Langa KM, Smith AK, et al.: Leveraging the health and retirement study to advance palliative care research. J Palliat Med 2014;17:506–511.
13. von Gunten CF, Teno JM, Sean Morrison R: Big data and end-of-life care: Promise and peril. J Palliat Med 2016;19:1240.
14. Bell JF, Fitzpatrick AL, Copeland C, et al.: Existing data sets to support studies of dementia or significant cognitive impairment and comorbid chronic conditions. Alzheimers Dement 2015;11:622–638.
15. *Diagnostic and Statistical Manual of Mental Disorders, 5th ed. American Psychological Association*. Arlington, VA: American Psychiatric Publishing, 2013.
16. Kasper JD, Freedman VA, Spillman B: Classification of persons by dementia status in the national health and aging trends study technical paper, No. 5. www.nhats.org/scripts/documents/DementiaTechnicalPaperJuly_2_4_2013_10_23_15.pdf (last accessed November 21, 2017).
17. Black SA, Espino DV, Mahurin R, et al.: The influence of noncognitive factors on the Mini-Mental State Examination in older Mexican-Americans: Findings from the Hispanic EPESE. Established population for the epidemiologic study of the elderly. J Clin Epidemiol 1999;52:1095–1102.
18. Kay DW, Dewey ME, McKeith IG, et al.: Do experienced diagnosticians agree about the diagnosis of dementia from survey data? The effects of informants' reports and interviewers' vignettes. Int J Geriatr Psychiatry 1998;13:852–862.
19. Bertens LC, Broekhuizen BD, Naaktgeboren CA, et al.: Use of expert panels to define the reference standard in

diagnostic research: A systematic review of published methods and reporting. PLoS Med 2013;10:e1001531.
20. Wilson RS, Weir DR, Leurgans SE, et al.: Sources of variability in estimates of the prevalence of Alzheimer's disease in the United States. Alzheimers Dement 2011;7:74–79.
21. Cullen B, O'Neill B, Evans JJ, et al.: A review of screening tests for cognitive impairment. J Neurol Neurosurg Psychiatry 2007;78:790–799.
22. Galvin JE, Roe CM, Xiong C, et al.: Validity and reliability of the AD8 informant interview in dementia. Neurology 2006;67:1942–1948.
23. O'Sullivan M, Morris RG, Markus HS: Brief cognitive assessment for patients with cerebral small vessel disease. J Neurol Neurosurg Psychiatry 2005;76:1140–1145.
24. Franco-Marina F, Garcia-Gonzalez JJ, Wagner-Echeagaray F, et al.: The Mini-mental State Examination revisited: Ceiling and floor effects after score adjustment for educational level in an aging Mexican population. Int Psychogeriatr 2010;22:72–81.
25. Goldberg TE, Harvey PD, Wesnes KA, et al.: Practice effects due to serial cognitive assessment: Implications for preclinical Alzheimer's disease randomized controlled trials. Alzheimers Dement (Amst) 2015;1:103–111.
26. Schussler-Fiorenza Rose SM, Xie D, Streim JE, et al.: Identifying neuropsychiatric disorders in the medicare current beneficiary survey: The benefits of combining health survey and claims data. BMC Health Serv Res 2016; 16:537.
27. Callahan CM, Tu W, Stump TE, et al.: Errors in self-reports of health services use: Impact on alzheimer disease clinical trial designs. Alzheimer Dis Assoc Disord 2015;29:75–81.
28. Bynum JP, Rabins PV, Weller W, et al.: The relationship between a dementia diagnosis, chronic illness, medicare expenditures, and hospital use. J Am Geriatr Soc 2004;52: 187–194.
29. Newcomer R, Clay T, Luxenberg JS, et al.: Misclassification and selection bias when identifying Alzheimer's disease solely from Medicare claims records. J Am Geriatr Soc 1999;47:215–219.
30. Taylor DH, Jr., Ostbye T, Langa KM, et al.: The accuracy of medicare claims as an epidemiological tool: The case of dementia revisited. J Alzheimers Dis 2009;17:807–815.
31. Feng Z, Coots LA, Kaganova Y, et al.: Hospital and ED use among medicare beneficiaries with dementia varies by setting and proximity to death. Health Aff (Millwood) 2014;33:683–690.
32. Mitchell SL, Kiely DK, Hamel MB, et al.: Estimating prognosis for nursing home residents with advanced dementia. JAMA 2004;291:2734–2740.
33. van der Steen JT: Dying with dementia: What we know after more than a decade of research. J Alzheimers Dis 2010;22:37–55.
34. Poppe M, Burleigh S, Banerjee S: Qualitative evaluation of advanced care planning in early dementia (ACP-ED). PLoS One 2013;8:e60412.
35. Patrick DL, Engelberg RA, Curtis JR: Evaluating the quality of dying and death. J Pain Symptom Manage 2001; 22:717–726.
36. Volicer L, Hurley AC, Blasi ZV: Scales for evaluation of end-of-life care in dementia. Alzheimer Dis Assoc Disord 2001;15:194–200.
37. Shega JW, Ersek M, Herr K, et al.: The multidimensional experience of noncancer pain: Does cognitive status matter? Pain Med 2010;11:1680–1687.
38. Herr K, Coyne PJ, Key T, et al.: Pain assessment in the nonverbal patient: Position statement with clinical practice recommendations. Pain Manag Nurs 2006;7:44–52.
39. Pautex S, Herrmann F, Le Lous P, et al.: Feasibility and reliability of four pain self-assessment scales and correlation with an observational rating scale in hospitalized elderly demented patients. J Gerontol A Biol Sci Med Sci 2005;60:524–529.
40. Pautex S, Michon A, Guedira M, et al.: Pain in severe dementia: Self-assessment or observational scales? J Am Geriatr Soc 2006;54:1040–1045.
41. Zwakhalen SM, Hamers JP, Berger MP: The psychometric quality and clinical usefulness of three pain assessment tools for elderly people with dementia. Pain 2006;126:210–220.
42. Lyketsos CG, Lopez O, Jones B, et al.: Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: Results from the cardiovascular health study. JAMA 2002;288:1475–1483.
43. Snow AL, Kunik ME, Molinari VA, et al.: Accuracy of self-reported depression in persons with dementia. J Am Geriatr Soc 2005;53:389–396.
44. Alexopoulos GS, Abrams RC, Young RC, et al.: Cornell scale for depression in dementia. Biol Psychiatry 1988;23: 271–284.
45. Boyle LL, Richardson TM, He H, et al.: How do the PHQ-2, the PHQ-9 perform in aging services clients with cognitive impairment? Int J Geriatr Psychiatry 2011;26:952–960.
46. Kroenke K, Spitzer RL, Williams JB, et al.: The patient health questionnaire somatic, anxiety, and depressive symptom scales: A systematic review. Gen Hosp Psychiatry 2010; 32:345–359.
47. Saliba D, DiFilippo S, Edelen MO, et al.: Testing the PHQ-9 interview and observational versions (PHQ-9 OV) for MDS 3.0. J Am Med Dir Assoc 2012;13:618–625.
48. Brodaty H, Connors MH, Xu J, et al.: Predictors of institutionalization in dementia: A three year longitudinal study. J Alzheimers Dis 2014;40:221–226.
49. van der Linde RM, Stephan BC, Dening T, et al.: Instruments to measure behavioural and psychological symptoms of dementia. Int J Methods Psychiatr Res 2014;23: 69–98.
50. Cummings JL, Mega M, Gray K, et al.: The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. Neurology 1994;44:2308–2314.
51. Juva K, Sulkava R, Erkinjuntti T, et al.: Staging the severity of dementia: Comparison of clinical (CDR, DSM-III-R), functional (ADL, IADL) and cognitive (MMSE) scales. Acta Neurol Scand 1994;90:293–298.
52. Gaugler JE, Yu F, Krichbaum K, et al.: Predictors of nursing home admission for persons with dementia. Med Care 2009;47:191–198.
53. Katz S: Assessing self-maintenance: Activities of daily living, mobility, and instrumental activities of daily living. J Am Geriatr Soc 1983;31:721–727.
54. Lawton MP, Brody EM: Assessment of older people: Self-maintaining and instrumental activities of daily living. Gerontologist 1969;9:179–186.
55. Guralnik JM, Simonsick EM, Ferrucci L, et al.: A short physical performance battery assessing lower extremity function: Association with self-reported disability and prediction of mortality and nursing home admission. J Gerontol 1994;49:M85–M94.

56. Tabue-Teguo M, Grasset L, Avila-Funes JA, et al.: Prevalence and co-occurrence of geriatric syndromes in people aged 75 years and older in France: Results from the Bordeaux Three-city Study. J Gerontol A Biol Sci Med Sci 2017; [Epub ahead of print]; DOI: 10.1093/gerona/glx068.
57. Kasper JD, Freedman VA, Spillman BC, et al.: The disproportionate impact of dementia on family and unpaid caregiving to older adults. Health Aff (Millwood) 2015;34: 1642–1649.
58. Viswanathan M, Berkman ND, Dryden DM, et al.: *Assessing Risk of Bias and Confounding in Observational Studies of Interventions or Exposures: Further Development of the RTI Item Bank.* Rockville, MD: Agency for Healthcare Research and Quality, 2013.
59. Kelley AS, Ettner SL, Morrison RS, et al.: Determinants of medical expenditures in the last 6 months of life. Ann Intern Med 2011;154:235–242.
60. Heiat A, Gross CP, Krumholz HM: Representation of the elderly, women, and minorities in heart failure clinical trials. Arch Intern Med 2002;162:1682–1688.
61. Mayeda ER, Glymour MM, Quesenberry CP, et al.: Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimers Dement 2016;12: 216–224.
62. Mielke MM, Vemuri P, Rocca WA: Clinical epidemiology of Alzheimer's disease: Assessing sex and gender differences. Clin Epidemiol 2014;6:37–48.
63. Herzog AR, Rodgers WL: Interviewing older adults: Mode comparison using data from a face-to-face survey and a telephone resurvey. Public Opin Q 1988;52:84–99.
64. Neumann PJ, Araki SS, Gutterman EM: The use of proxy respondents in studies of older adults: Lessons, challenges, and opportunities. J Am Geriatr Soc 2000;48:1646–1654.
65. van Herk R, van Dijk M, Biemold N, et al.: Assessment of pain: Can caregivers or relatives rate pain in nursing home residents? J Clin Nurs 2009;18:2478–2485.
66. Ofstedal MB, Fisher GG, Herzog AR: Documentation of Cognitive Functioning Measures in the Health and Retirement Study. Ann Arbor, MI: University of Michigan Survey Research Center, 2005. http://hrsonline.isr.umich.edu/sitedocs/userg/dr-006.pdf (last accessed November 21, 2017).
67. Hurd MD, Martorell P, Delavande A, et al.: Monetary costs of dementia in the United States. N Engl J Med 2013;368: 1326–1334.
68. Langa K, Kabeto M, Weir D: Report on Race and Cognitive Impairment Using HRS in 2010 Alzheimer's Disease Facts and Figures. www.alz.org/documents_custom/report_alzfactsfigures2010.pdf (last accessed November 21, 2017).
69. Ornstein KA, Aldridge MD, Mair CA, et al.: Spousal characteristics and older adults' hospice use: Understanding disparities in end-of-life care. J Palliat Med 2016;19:509–515.
70. Hunt LJ, Covinsky KE, Yaffe K, et al.: Pain in community-dwelling older adults with dementia: Results from the National Health and Aging Trends Study. J Am Geriatr Soc 2015;63:1503–1511.
71. Hong CH, Falvey C, Harris TB, et al.: Anemia and risk of dementia in older adults: Findings from the Health ABC study. Neurology 2013;81:528–533.
72. Miller SC, Lima JC, Looze J, et al.: Dying in U.S. nursing homes with advanced dementia: How does health care use differ for residents with, versus without, end-of-life Medicare skilled nursing facility care? J Palliat Med 2012;15:43–50.
73. Taylor DH, Jr., Fillenbaum GG, Ezell ME: The accuracy of medicare claims data in identifying Alzheimer's disease. J Clin Epidemiol 2002;55:929–937.
74. Willis AW: Using administrative data to examine health disparities and outcomes in neurological diseases of the elderly. Curr Neurol Neurosci Rep 2015;15:75.

Address correspondence to:
Lauren J. Hunt, MSN
Department of Physiological Nursing
University of California, San Francisco
San Francisco, CA 94143

E-mail: lauren.hunt@ucsf.edu