

Existing data sets to support studies of dementia or significant cognitive impairment and comorbid chronic conditions

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Abstract

Background: Dementia or other significant cognitive impairment (SCI) are often comorbid with other chronic diseases. To promote collaborative research on the intersection of these conditions, we compiled a systematic inventory of major data resources.

Methods: Large data sets measuring dementia and/or cognition and chronic conditions in adults were included in the inventory. Key features of the resources were abstracted including region, participant sociodemographic characteristics, study design, sample size, accessibility, and available measures of dementia and/or cognition and comorbidities.

Results: 117 study data sets were identified; 53% included clinical diagnoses of dementia along with valid and reliable measures of cognition. Most (79%) used longitudinal cohort designs and 41% had sample sizes greater than 5000. Approximately 47% were European-based, 40% were US-based, and 11% were based in other countries.

Conclusions: Many high-quality data sets exist to support collaborative studies of the effects of dementia or SCI on chronic conditions and to inform the development of evidence-based disease management programs.

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Keywords:

Public health; Databases; Secondary Data analysis; Dementia; Cognitive impairment; Multiple; Chronic conditions

1. Introduction

The dramatic increase in the number of adults greater than the age of 65 years around the world and the concomitant increase in the prevalence of multiple chronic condi-

tions are major public health concerns [1-6]. Individuals with multiple chronic conditions have poor functional status, greater use of health services and related expenditures, inadequately coordinated care, and higher risk of mortality [1,2,7-13].

Dementia and significant cognitive impairment (SCI) are chronic conditions and the number of people with Alzheimer's disease (AD) and other forms of dementia is expected to almost triple by 2050 [14,15]. Relationships

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between dementia or SCI and comorbid chronic conditions are complex. Many conditions associated with aging, including cardiovascular disease, have been identified as risk factors for dementia or SCI [16–18]. Conversely, we know less about dementia and SCI as risk factors for other chronic conditions. Most large population-based cohort studies comparing demographically matched older adults with and without dementia or SCI suggest that those affected are more likely to suffer from multiple comorbid conditions; have a higher burden of illness; experience more adverse outcomes (including injuries from falls); use more health care (including inpatient services for ambulatory care sensitive conditions, hospital readmissions, prescription fills, emergency department visits, and home health care); and incur higher related expenditures [19–30]. These findings may be due, in part, to effects on memory, language, judgment, and reasoning ability among older adults with dementia or SCI which, in turn, lead to difficulties recognizing and reporting symptoms, adhering to medication, reporting side effects, and complying with treatment and follow-up recommendations [19,31,32].

Taken together, the unique challenges for chronic disease management, greater burden of disease, and higher health care expenditures experienced by older adults with dementia or SCI, lend new urgency to the need for evidence-based prevention and health promotion efforts that optimize cognitive and physical health in this population. In a recent report, *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships*, the US Centers for Disease Control and Prevention (CDC) called for improved understanding and reporting of the public health burden of dementia and SCI and for increased related data collection and monitoring efforts from health surveillance programs [33].

In a systematic review examining the prevalence and effects of dementia or SCI on co-occurring chronic conditions, our team identified several research priorities, including the need for studies of: (1) service use; (2) associations between multiple chronic conditions and disease-specific outcomes; and (3) evaluation of dementia or SCI with specific chronic conditions (e.g., diabetes, chronic pain, cardiovascular disease, depression, falls or fractures, and stroke) [34]. Many studies worldwide have collected data on dementia or SCI and multiple risk factors. Informing the research community of these studies and their data resources could promote collaborations with or without data sharing and encourage new research [35].

To stimulate secondary data analyses designed to address gaps in the literature addressing cognitive decline and co-occurring chronic conditions, we conducted a systematic inventory of major data sets that included measures of dementia and/or cognition and chronic conditions in adults. Intended as a resource for the research community, this inventory is expected to facilitate collaborative studies of the effects of dementia or SCI on chronic conditions and to support the design and delivery of evidence-based disease management programs that address the implications of

increasing rates of dementia and SCI among older adults. This inventory should promote use of high quality data to answer critical research questions and encourage new collaborations and networks that ultimately integrate resources and promote data sharing across studies.

2. Methods

We formed an interdisciplinary advisory panel comprising experts in gerontology, clinical medicine, psychiatry, psychology, epidemiology, health services research and biostatistics to oversee the development of an inventory of data sets appropriate for the study of cognition and co-occurring diseases. Experts were selected by the study principal investigators (MS, AF) in consultation with leaders of the CDC's Healthy Aging Program in the Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion. Specific expert panel goals were to guide the:

1. Identification and evaluation of potential data sets;
2. Development of criteria for data set inclusion and a data abstraction tool;
3. Identification and characterization of included data sets;
4. Compilation of a publicly available inventory of data sets including:
 - a. study characteristics (e.g., design, sample size, length of follow-up);
 - b. participant characteristics (e.g., sex, race/ethnicity);
 - c. measures of dementia or cognition and chronic conditions; and
 - d. information required for data set access.

2.1. Inclusion criteria

Based on guidance from the expert panel, criteria for data sets to be included were: (1) study population inclusive of adults aged 50 and older; (2) at least 500 participants; (3) documentation available in English; (4) a valid and reliable clinical diagnosis of dementia (i.e., using the Diagnostic Statistical Manual criteria, 4th edition [DSM-IV] [35] or other standardized criteria [41,42]) and/or one or more valid and reliable measures of cognition capturing memory and at least one other cognitive domain such as executive function or language (e.g., Mini-Mental Status Examination [MMSE]) [34]; and (5) at least one of the following: (a) a measure of at least one chronic condition (i.e., conditions lasting a year or more and requiring ongoing medical attention and/or limiting activities of daily living [3]) derived from physical examination, International Classification of Diseases (ICD) codes or medical history/self-report; (b) a valid and reliable measure of comorbidity (e.g., Charlson Comorbidity Index [36]); or (c) valid and reliable measures of geriatric syndromes [37–39] such as falls, frailty,

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