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Review Article

Review of selected databases of longitudinal aging studies

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Abstract One of the recommendations of the 2010 Leon Thal Symposium, organized to develop strategies to prevent Alzheimer's disease, was to build a global database of longitudinal aging studies. Although several databases of longitudinal aging studies exist, none of these are comprehensive or complete. In this article, we review selected databases of longitudinal aging studies. We also make recommendations on future steps to create a comprehensive database. Additionally, we discuss issues related to data harmonization.

Keywords: Longitudinal study; Aging; Aged; Biomarkers; Database

1. Background

One of the four major recommendations from the 2010 Leon Thal Symposium, which brought together experts in brain aging and dementia to examine national strategies to prevent Alzheimer's disease (AD), was "… initiation of a Global Database that extends the concept of the National Database for Longitudinal Studies for longitudinal studies beyond the United States;" [1].

As implied in the aforementioned recommendations, creation of a global database of longitudinal aging studies is crucial to facilitating large collaborative studies and providing the research community with the greatest opportunity to conduct efficient, optimally informed research. Multiple longitudinal aging studies exist around the world that could contribute valuable data to such a database [2,3]. Currently, a few databases have systematically collected and stored data/information from two or more longitudinal aging studies. These databases were created for different purposes, and the amount and type of data they provide vary. Additionally, how useful these databases are to the research community in general is unclear. This review aims to answer several questions related to these databases: Which are the main databases that include data on or information about longitudinal aging studies? Are these databases used in their current format? What future steps should be taken to improve the utilization of such databases? To try to answer these questions, this article reviews selected databases and makes recommendations for future attempts in creating a database of longitudinal aging studies.

2. Identification of databases

We aimed to identify all Web-based databases that provide either individual-level data from longitudinal aging studies or information on which longitudinal aging study includes what types of variables. To find Web-based databases, the majority of which do not have a related publication, we used Internet searches and relied on discussions with experts in the field to obtain a comprehensive list.

Existing databases were identified through Web searches, using the Internet search engines "Google" and "Google scholar," conducted on December 15, 2010 and June 27, 2011. The following search terms were used: "aging database," "Alzheimer disease," "Alzheimer's disease," "longitudinal aging study," "aging study network," or "longitudinal study on aging." Sites not related to human aging research

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were excluded. We also repeated our search using MEDLINE for years 1946 through the last 3 weeks of June 2011, using the same search phrases. Our search did not identify any additional Web sites. In fact, most of the databases or other aging-relevant Web sites were not captured using this method. The list was further compiled from discussions with experts in the field.

From this extensive list, we only selected for review databases that (1) focused on brain aging, (2) included studies with biomarker measures, and (3) are publicly available as a Web-based database.

3. Databases

Our search yielded more than 100,000 sites. From this list, we first compiled a table including all Web sites/networks that were related to human aging research, available in English, and had a searchable Web-based database (Table 1). The sites/networks/databases without a Web-based searchable database, but relevant to human aging research, are presented separately (Supplementary Table 1). The focus and collection methods of these databases/networks vary widely. While some gather aging-related survey data with a focus on qualitative measures and policy issues, some focus on publications and resources relevant to aging. Others include information on cognitive or biomarker variables from longitudinal aging studies. Several of the databases focus on genetics of aging. Some of these databases provide information about what measures are available from different longitudinal aging studies, whereas others provide data at the individual subject level. A few of these databases are private, where data are not available to nonaffiliated investigators (Supplementary Table 1). In the end, from the list of sites in Table 1, the following databases were selected for further review based on their focus on the aging brain, biomarker annotation, and public availability as a searchable Web site of the database: the National Institute on Aging (NIA) Database of Longitudinal Studies (DLS) [4], Cognitive and Emotional Health Project (CEHP) [5], the Integrative Analysis of Longitudinal Studies on Aging (IALSA) [6,7], the National Alzheimer Disease Coordinating Center (NACC) database [8], and the Alzheimer Disease Neuroimaging Initiative (ADNI) database [9]. NACC and ADNI differ from the other databases because they provide data sets at the individual subject level and focus on AD. Additionally, ADNI is not a "database" in the true sense. However, because both include cognitive and biomarker data obtained from multiple longitudinal aging studies, we believed they were relevant to this review.

The NIA-DLS resulted from the recommendations of the 2003 NIA Longitudinal Data on Aging working group [4]. This group was assembled to facilitate research initiatives to identify risks and protective factors for diseases associated with brain aging. As a first step, the working group recommended establishing a database of existing sources of longitudinal aging-related data. The primary purpose of the database was to establish a resource for investigators applying for NIA grants. The NIA-DLS includes a total of 55 longitudinal studies. Data from the Canadian Institutes of Health Research (CIHR) review of Longitudinal Studies on Aging were used in the development of the NIA database [10]. The CIHR review resulted from a review of longitudinal studies on aging undertaken by the Division of Aging and Seniors, Health Canada. The CIHR review does not have a Web-based database, but it resulted in a document that includes information on the design and current status of the studies and study variable domains. In contrast, the NIA database is a Web-based searchable database and provides information on which studies have collected which variables. How studies were selected to be included in the NIA-DLS is not described. Although most studies included focus on brain aging, some of the studies enrolled younger subjects and did not include brain aging as the main focus (such as the Canadian Multicentre Osteoporosis Study or the Bogalusa Heart Study; Supplementary Table 2). Two reviews of longitudinal studies on aging have concluded that some studies with valuable findings were not included in the NIA-DLS [3,11]. One such study, for example, is the well-known Framingham study.

The CEHP, initiated in 2001, is another Web-based searchable database supported by the NIA, the National Institute of Mental Health, and the National Institute of Neurological Disorders and Stroke. Its aim is to "…assess the state of longitudinal and epidemiological research on demographic, social and biologic determinants of cognitive and emotional health in aging adults" [5]. Unlike other databases, CEHP has well-defined selection criteria: studies were included if they had a sample size of $>$500 subjects, and studied a broad range of demographic, biological, and psychosocial risk factors. However, the CEHP database is not limited to studies focusing on middle-aged or elderly individuals. Longitudinal studies with a focus on brain health and enrolling young adults, for example, have also been included. Examples of such studies are the San Antonio Lupus Study of Neuropsychiatric Disease, the Work and Iron Status Evaluation, and the neurobiological studies of Huntington disease (Supplementary Table 2). A Web-based searchable questionnaire database was created based on the responses to a questionnaire sent to 80 studies, not all of which had a focus on age-related cognitive changes. Additionally, not all of the studies had a sample size of $>$500 subjects, as initially mentioned in the inclusion criteria. The CEHP database also provides information on constituent variables of the participating studies.

The IALSA network, whose meta-data tool development started in 2005, aims to create "…a collaborative research infrastructure for coordinated interdisciplinary, cross-national research aimed at the integrative understanding of within-person aging-related changes in health and cognition" [6,7]. It is an open and growing network, and more than 25 longitudinal aging studies from around the world have joined this network [12]. The IALSA database provides