A disease registry is an organized system in which uniform data (clinical and nonclinical) are gathered to assess the outcomes in a given population with a particular disease, condition, or exposure to disease (1). Use of registry systems can provide a better understanding of the natural history of a disease and offer treatment instructions for patients and organizations (2). Analysis of the registered data in these systems can be used to present activity reports, propose research hypotheses, and improve patient care (3).

Population aging is one of the most important health concerns worldwide, associated with certain consequences, outcomes, and costs (4). As a result, healthcare systems require effective strategies to improve the process of healthcare provision to meet the needs of the elderly (5). Increased life expectancy and significant growth in the elderly population are associated with increased prevalence of chronic diseases such as dementia (6).

Alzheimer disease (AD) is one of the most common causes of dementia in people aged over 65 years (7). AD is a degenerative disease that causes various social, economic, and psychological problems for the elderly and their families (8). In addition, according to statistics, nearly 46 million people have dementia worldwide, which is speculated to reach 130 million people by 2050 (9).

Use of dementia and AD registry systems is a standard method for data collection and is considered a reliable source of information (10). The purpose of AD registries is to collect information to identify, locate, and analyze the incidence, frequency, prevalence, etiology, outcome, and prognosis of AD (11). In addition, the information and reports in these systems can be used to run surveillance studies, perform epidemiological research (to identify the risk factors for the pathogenesis of AD and dementia), plan healthcare services, and improve disease diagnosis and...
treatment (12).

Use of different dementia and AD registry systems, at the state and local levels, dates back to the 1980s in the United States. These systems aimed at improving the statistical power of clinical research in this area (13-20). The consortium to establish a registry for Alzheimer disease (CERAD), a national registry system, was developed in the 1980s to standardize disease assessment procedures and improve epidemiological studies (21, 22). Many initiatives are undertaken in other countries, such as the United Kingdom (23), Spain (10), and France (3), to collect data on patients undergoing dementia and AD. Despite major efforts to develop AD and dementia registries, no international standards are proposed for these systems (24). Furthermore, only few comparative studies are conducted on the structure of these systems (12, 25, 26), and no systematic review is so far performed in this area. Therefore, review of the available registries and studies in this area can play a significant role in the collection and presentation of findings to design and develop such systems. The current study, as the 1st systematic review, aimed at focusing on AD and dementia registries and summarizing the required characteristics such as the objectives, resources, sampling procedures, minimum data sets (MDSs), and data quality to promote the design and implementation of such systems in other healthcare contexts.

2. Evidence Acquisition

2.1. Search Strategy

The current systematic review searched for studies published in English with no time limitations, using the following databases: Institute of electrical and electronics engineers (IEEE), ProQuest, PubMed, Science Direct, Web of Science, Scopus, Ovid Medline, Scientific Information Database (SID), and IranMedex. The final search was performed on 07 February, 2017, using a combination of keywords and mesh terms related to AD, ie, “Alzheimer disease” and “dementia”, and registry systems, ie, “database” and “registries” (along with Boolean operators AND/OR in the title). The details of the search strategy are available in supplementary file Appendix I for each database. In addition, the study adhered to the protocol to review articles, based on preferred items to report in systematic reviews (PRISMA) (27).

3. Study Selection

First, based on the search strategy, a total of 799 articles were retrieved. No article was found in the SID and IranMedex databases. Overall, there were 483 duplicates among the databases, which were excluded. In the next step, the abstract and title of 316 articles were studied with respect to the inclusion criteria. Screening of titles and abstracts was conducted independently by 2 researchers and the Cohen Kappa coefficient was used to compare the consistency (k = 0.87). The disagreement between researchers was resolved by consensus. To prevent assessment bias, researchers were blind to journal name, the author name, and the decision of each other.

The inclusion criteria in the present study were: journal articles and conference proceedings related to dementia and AD registries and databases, and being published in English. On the other hand, since there are no distinct classifications for registry systems, the study was mainly focused on dementia and AD registries, excluding prevention registries, risk registries, research registries, gene databases, and skill and resource registries, based on the classification proposed by Weddell (28). Editorials and letters to editors were also excluded.

At this stage, 233 articles were excluded, considering the irrelevance of the article title or abstract. The full texts of 103 articles, which seemed relevant to the objectives, were reviewed by 3 researchers. Any disagreement was resolved by consensus. To identify the articles, the references of all articles were also reviewed. Figure 1 presents the process of study selection. In addition, to include the gray literature in the current review, the websites of registry systems identified in the final stage as well as their forms and annual reports were also assessed.

4. Data Extraction

In the current review article, different registry systems were evaluated based on a checklist with variables and data items presented in Table 1. They included the title of the registry system, year of implementation, country of origin, current status of the system, main objectives based on use (29), type of data sources (30), minimum data set (MDS) (31), and data quality (32). The validity of this checklist in extracting main data items in the registries was assessed by 2 independent researchers. Based on the current study aims and objectives, only the qualitative variables from the included studies were extracted (Table 1). As there was little consensus on assessing the quality of qualitative studies to include in a review (33-35), the quality of included studies was not assessed.

5. Results

Following the literature search and final analysis, 28 articles, considered eligible, were included (3, 10-24) (36-47).
Studies identified through databases searching (n = 799)
Duplicate studies removed (n = 483)
Exclusions based on title and abstract review (n = 213)
Studies screened (n = 316)
Exclusions based on full-text (n = 77)
Full-text articles assessed (n = 103)
Studies included (n = 28)
Studies found by hand search (n = 2)

Figure 1. Flow Chart for the Study Selection

In addition, annual reports and records, extracted from the registries websites, were examined for complementary information (48-50). Overall, 22 dementia and AD registries were identified at the national, state, and local levels in different countries from 1986 to 2014. Table 2 presents the information extracted from these databases and registries, including the purpose of the registry based on use, basic registry information, data sources, MDSs, and data quality.

Based on the extracted data, the highest frequency of dementia and AD registries was reported in North America (n = 13) (13-21, 42-44, 46). Based on the analyses, most information in this region was reported at the local and state levels; in addition, Europe (n = 7) (3,10, 23, 24, 38-40), Asia (n = 1) (37), and South America (n = 1) (12) followed North America. However, no AD or dementia registry, meeting the inclusion criteria, was found in Africa. Meanwhile, among the extracted registries, 9 were implemented in the 1980s (13-21).

In half of the registry systems, patient recruitment was performed among inpatients and outpatients in a variety of healthcare centers, including hospitals, specialized clinics, elderly care centers, and research centers (10-12, 14, 17, 20, 23, 37, 40, 41, 44). Furthermore, based on the analysis of these systems, 13 had active systems (3,10, 11, 14, 16-17, 19-21, 23, 24, 37-41, 43, 44), while 3 were the pilot trials (12, 24, 44).

With regard to basic and structural information in the registries, the extracted data were somehow inconsistent in terms of objectives, data sources, and MDS. The majority of registries (n = 20) were implemented with clinical and epidemiological purposes to analyze the effectiveness of clinical care and present comprehensive information to formulate policies and planning (3,10-12, 14-17, 19-21, 23, 24, 37-41, 43, 44).

With respect to data sources in registry systems, 16 population-based registries were reported (3, 11, 12, 14, 16-20, 22, 24, 38, 41, 43-45). MDSs were also evaluated, among which only 8 met all 4 characteristics of patient and service provider, as well as diagnostic and treatment parameters (3,10-12, 21, 38, 46, 49).

Regarding data completeness, a total of 10 articles reported this feature (3, 10, 11, 16, 38-41, 45, 50). Moreover, in terms of diagnostic criteria, the international classification of diseases, revisions 9 and 10 (ICD-9 and ICD-10) were identified as the most prevalent diagnostic codes in 8 registries (3, 12, 14, 20, 38, 40, 49, 50).

6. Discussion

The current study was the first systematic review providing a global overview on dementia and AD registries and summarizing the required characteristics to design and implement these systems. The results of the comparisons indicated inconsistency in the structural characteristics of dementia and AD registries, particularly in areas such as domain coverage, objectives, data sources, data type, and diagnostic criteria.
Table 1. Data Elements

<table>
<thead>
<tr>
<th>Category</th>
<th>Data Element</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic registry information</td>
<td>Full name, acronym, country, year of establish, number of patients, type of patients (outpatient, inpatient), reporting, status</td>
</tr>
<tr>
<td>Purpose of registry based on use</td>
<td>Clinical, epidemiology, research, surveillance</td>
</tr>
<tr>
<td>Data source of registry</td>
<td>Local registry hospital (1 hospital)</td>
</tr>
<tr>
<td></td>
<td>Central registry (selected hospitals within a region (city, state)</td>
</tr>
<tr>
<td></td>
<td>Population-based (all cases in population of known size and composition)</td>
</tr>
<tr>
<td>MDS (A standard tool for data collection)</td>
<td>Diagnostic characteristics (heredity, BMI, MMSE Score, type of Alzheimer, history of other disorder, history of depressive disorder, a history of Alzheimer disease and related disorders, blood test, clock-test, CT, MRI)</td>
</tr>
<tr>
<td></td>
<td>Treatment characteristics (pharmacological treatment, number of drugs, non-pharmacological treatment)</td>
</tr>
<tr>
<td>Data quality</td>
<td>Completeness of data (the proportion of all cases in the defined population)</td>
</tr>
<tr>
<td></td>
<td>Validity of diagnostic coding (stringent criteria for diagnosis)</td>
</tr>
</tbody>
</table>

Abbreviations: BMI, body mass index; CT, computed tomography; MDS, mini mental state examination; MRI, magnetic resonance imaging.

Based on the current findings, in recent years, the geographical coverage of dementia and AD registries extended from the local and state levels to the national scale. In addition, the majority of these registries were developed with the purpose of improving epidemiological studies, evaluation processes, and clinical procedures (3, 10-12, 14-17, 19-21, 23, 24, 37-41, 43, 44). In recent years, considering the rapid pace of population aging and the importance of longitudinal and prospective studies to progress clinical procedures and presentation of research hypotheses, there is a major focus on the development of registries with an emphasis on research (3, 15, 18, 19, 24, 37, 38, 41, 45) and surveillance (10, 11).

The current study revealed the lack of uniformity in data types and sources. In the registry systems, demographic, diagnostic, and treatment information was heterogeneous, with respect to the geographical coverage, range of activities, and different diagnostic, therapeutic, and assessment methods (25, 26). Meanwhile, the impact of factors such as cost, source of funding, and the required time for system implementation should not be neglected (1).

Data quality was another important factor in the current study. Although different methods of data quality assessment are available for registries (particularly data validity and completeness presented by Goldberg) (32), few studies are performed regarding the implementation of these methods and few articles focus on data validity and data completeness in dementia and AD registries (51). In fact, these 2 parameters are among the biggest challenges against the implementation of disease registries (11).

In the majority of the registries reviewed in the present study, data completeness was observed to some extent, regarding the target population of the registry, data sources, and consistency among databases and registries (10, 11, 16, 40, 41, 45, 50). In addition, in some of these registries, data completeness was manually evaluated by experts (3, 38, 39).

In the current study, the comparison of diagnostic coding validity was somehow different from other characteristics, considering the use of different standard diagnostic coding systems, including the criteria proposed by the national institute of neurological and communicative disorders and stroke and the Alzheimer disease and related disorders association, the diagnostic and statistical manual of mental disorders, 4th Edition, and the ICD-10 for the diagnosis and treatment of AD, as the most prevalent type of dementia (52). In addition, it should be noted that different diagnostic criteria for different subtypes of dementia were applied, including the movement disorder society task force criteria (53), the McKeith criteria (54), and the Lund-Manchester criteria (55). Overall, the application of these classification systems and diagnostic codes increases the chance of various diagnostic decisions (56). However, factors such as the development and promotion of guidelines to diagnose AD and the identification of disease stage can be effective in the use of these different coding systems (52).

The present study was the 1st review of dementia and AD registries. Despite the comprehensive review performed in the current study through combining different keywords, the study had certain limitations. First, the focus of the study was only on articles related to disease registries, while other registries such as research registries, risk registries, gene databases, and prevention registries were disregarded based on the exclusion criteria. Second, in the current study, only articles written in English were reviewed; therefore, there was a possibility of missing
some relevant data in articles that published in other languages. Third, in the review of the extracted registries, all the variables involved in the assessment of registries (such as the reporting method) could not be studied due to the scarcity of information in the extracted articles and lack of access to reports on registries.

7. Conclusions

Today, registry systems, in addition to providing valuable information for the promotion of treatment and educational services can facilitate qualitative and quantitative developments and promote cooperation among clinicians and research groups. Nevertheless, in the present review, the extracted registries differed in terms of objectives, user domain, and structural features. Therefore, analysis and comparison among these systems could be effective in developing and expanding dementia and AD registries.

Supplementary Material

Supplementary material(s) is available here [To read supplementary materials, please refer to the journal website and open PDF/HTML].

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Footnotes

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References


<table>
<thead>
<tr>
<th>Region</th>
<th>Country, Coverage</th>
<th>Registry Name, Year of Establish</th>
<th>Purpose of Registry</th>
<th>Type of Patients</th>
<th>Data Source</th>
<th>MDS</th>
<th>Data Quality</th>
<th>Current Status</th>
</tr>
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<tr>
<td>Asia (n = 4)</td>
<td>South Korean, National</td>
<td>Clinical Research Center for Dementia of South Korea Registry (CREDOS), 2010 (36, 37)</td>
<td>Clinical, epidemiological, research</td>
<td>OP/IP</td>
<td>CR</td>
<td>PC, SPC, DC</td>
<td>NP</td>
<td>NINCDS-ADRDA, DSM-IV</td>
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<td></td>
<td>Germany, National</td>
<td>German Population-based Dementia Registry, 2008 (34)</td>
<td>Clinical, epidemiological, research</td>
<td>OP</td>
<td>PB</td>
<td>PC, SPC, DC</td>
<td>NP</td>
<td>NP</td>
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<tr>
<td></td>
<td>France, National</td>
<td>The French National Alzheimer Database, 2009 (3)</td>
<td>Clinical, epidemiological, research</td>
<td>OP/IP</td>
<td>CR</td>
<td>PC, SPC, DC, TC</td>
<td>Yes</td>
<td>ICD-10, MKC, LMC, MDSTFC</td>
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<td></td>
<td>Sweden, National</td>
<td>Swedish Dementia Registry (SveDem), 2007 (38)</td>
<td>Clinical, epidemiological, research</td>
<td>OP</td>
<td>PB</td>
<td>PC, SPC, DC, TC</td>
<td>Yes</td>
<td>ICD-10, MKC, LMC, MDSTFC</td>
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<tr>
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<td>Spain, Local (Girona)</td>
<td>Registry of Dementias of Girona (ReDeGi), 2007 (10)</td>
<td>Clinical, epidemiological, surveillance</td>
<td>OP/IP</td>
<td>CR</td>
<td>PC, SPC, DC, TC</td>
<td>Yes</td>
<td>DSM-IV-TR, MKC, LMC, MDSTFC, NINDS-SPSP</td>
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<td></td>
<td>Denmark, Local (Copenhagen)</td>
<td>Danish dementia assessment quality database, 2005 (35)</td>
<td>Clinical, epidemiological</td>
<td>OP</td>
<td>CR</td>
<td>DC, DC, TC</td>
<td>Yes</td>
<td>NP</td>
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<td></td>
<td>USA, State (Georgia)</td>
<td>Georgia’s Alzheimer Disease Registry, 2004 (44, 45)</td>
<td>Clinical, epidemiological research</td>
<td>OP/IP</td>
<td>PB</td>
<td>PC, SPC, DC</td>
<td>Yes</td>
<td>NP</td>
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<tr>
<td></td>
<td>USA, State (West Virginia)</td>
<td>The West Virginia Alzheimer Disease Registry, 2010 (44, 45)</td>
<td>Clinical, epidemiological</td>
<td>OP/IP</td>
<td>PB</td>
<td>PC, SPC, DC, TC</td>
<td>NP</td>
<td>ICD-10, ICD-9</td>
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<td>Canada, Local (Toronto)</td>
<td>Canadian dementia care registry, 2004 (44)</td>
<td>Clinical, epidemiological</td>
<td>OP/IP</td>
<td>PB</td>
<td>PC, SPC, DC</td>
<td>NP</td>
<td>NP</td>
</tr>
<tr>
<td></td>
<td>USA, National</td>
<td>National Alzheimer Coordinating Center (NACC) Database, 2004 (44)</td>
<td>Research</td>
<td>OP</td>
<td>PB</td>
<td>PC, SPC, DC, TC</td>
<td>Yes</td>
<td>NP</td>
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<td></td>
<td>USA, State (South Carolina)</td>
<td>The South Carolina Alzheimer Disease Registry, 1994 (34, 35)</td>
<td>Clinical, epidemiological</td>
<td>OP/IP</td>
<td>PB</td>
<td>PC, SPC, DC</td>
<td>Yes</td>
<td>ICD-8</td>
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<td>The Florida Dementia Registry, 1987 (8)</td>
<td>Clinical, epidemiological, research</td>
<td>OP/IP</td>
<td>PB</td>
<td>PC, SPC, DC, TC</td>
<td>NP</td>
<td>NP</td>
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<td>USA, State (New York)</td>
<td>New York State Dementias registry, 1944 (46, 47)</td>
<td>Clinical, epidemiological, surveillance</td>
<td>OP/IP</td>
<td>CR</td>
<td>PC, SPC, DC</td>
<td>NP</td>
<td>NP</td>
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<td></td>
<td>USA, Local (Los Angeles)</td>
<td>Mayo Clinic Alzheimer Disease Patient Registry, 1984 (45)</td>
<td>Clinical, epidemiological,</td>
<td>OP/IP</td>
<td>PB</td>
<td>PC, SPC, DC</td>
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<td>NINCDS-ADRDA</td>
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<td>USA Local (Seattle)</td>
<td>The University of Washington Alzheimer Disease Patient Registry, 1984 (45)</td>
<td>Clinical, epidemiological</td>
<td>OP/IP</td>
<td>PB</td>
<td>PC, DC</td>
<td>NP</td>
<td>DS0-ER, NINCDS-ADRDA</td>
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<td>Source of Data</td>
<td>The University of Pittsburgh Alzheimer Disease Patient Registry, 1986 (18)</td>
<td>Research</td>
<td>OP</td>
<td>PB</td>
<td>PC, DC</td>
<td>NP</td>
<td>DSM-III-R</td>
<td>NP</td>
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<td>North America (n = 48) USA, Local (Pittsburgh)</td>
<td>The East Boston Alzheimer Disease Registry, 1986 (19)</td>
<td>Clinical, epidemiology, research</td>
<td>OP</td>
<td>PB</td>
<td>PC, DC, PC</td>
<td>NP</td>
<td>DSM-III-R, NINCDS-ADRDA</td>
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<td>USA, Local (East Boston)</td>
<td>The East Boston Alzheimer Disease Registry, 1986 (19)</td>
<td>Clinical, epidemiology, research</td>
<td>OP</td>
<td>PB</td>
<td>PC, DC</td>
<td>NP</td>
<td>DSM-III-R, NINCDS-ADRDA</td>
<td>NP</td>
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<td>USA, Local (Iowa)</td>
<td>Iowa Alzheimer Disease Registry, 1986 (20)</td>
<td>Clinical, epidemiological</td>
<td>OP/IP</td>
<td>PB</td>
<td>PC, DC</td>
<td>NP</td>
<td>ICD-9, NINCDS-ADRDA</td>
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<td>USA, National</td>
<td>Consortium to Establish a Registry for Alzheimer Disease (CERAD), 1986 (21-24)</td>
<td>Clinical, epidemiological</td>
<td>OP</td>
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<td>PC, DC, TC</td>
<td>NP</td>
<td>NINCDS-ADRDA</td>
<td>Active</td>
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<tr>
<td>South America (n = 4) Cuba, National</td>
<td>Cuban Registry of Cognitive Impairment and Dementia (ReCeDemCu), 2015 (12)</td>
<td>Clinical, epidemiological</td>
<td>OP/IP</td>
<td>PB</td>
<td>PC, DC, TC</td>
<td>NP</td>
<td>ICD-9, ICD, NINCDS-ADRDA, NINDS-SPSP, NINDS-APC</td>
<td>Active</td>
</tr>
</tbody>
</table>

Abbreviations: C, completeness; CR, central registry; DC, diagnostic characteristics; DCV, diagnostic criteria validity; DSM-III-R, diagnostic and statistical manual of mental disorder, 3rd edition; DSM-IV, diagnostic and statistical manual of mental disorder, 4th edition; ICD-10, the 10th revision of the international classification of diseases; IP, inpatient; ICD, the International Classification of Diseases; LRH, local registry hospital; MDS, minimum data set; MKC, the McKeith criteria; MDSTFC, movement disorder society task force criteria; NINDS-ADRDA, national institute of neurological and communicative disorders and stroke, and Alzheimer disease and related disorders association; NINDS-SPSP, clinical research criteria for the diagnosis of progressive supranuclear palsy; NP, no published data available; OP, outpatient; PB, population-based; PC, patient characteristics; SPC, service provider characteristics; TC, treatment characteristics.