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# Role of Alzheimer Disease National Registry System in Prevention and Treatment Management

**Sima Ajami**[1*], **Mehri Nemati-Shahpar**[2] **and Ahmad Chitsaz**[3]

*[1]Department of Health Information Technology and Management, School of Medical Management and Information Sciences, Isfahan University of Medical Sciences, Iran*

*[2]Department of Medical Records in Imam Reza Hospital, Hamadan University of Medical Sciences, Hamadan, Iran*

*[3]Department of Neurology, School of Medicine, Isfahan University of Medical Sciences, Hezarjerib Avenue, Isfahan, Iran*

[*]**Corresponding author:** Sima Ajami, Department of Health Information Technology and Management, School of Medical Management and Information Sciences, Isfahan University of Medical Sciences, Hezarjerib Avenue, Iran, Tel: +98-31- 36684799; E-mail: ajami@mng.mui.ac.ir

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## Abstract

Alzheimer is a kind of brain disorder in which death of brain cells leads to dysfunction of memory, thought, judgment, language, and other nervous activities which can subsequently change individual behavior and personality. Collection of proper data and access to sufficient information regarding causes of Alzheimer can help to develop preventive programs and manage treatment. The most important part of information management system is data collection which is considered as the basic tool for a detailed description of the health care process, evaluation, diagnosis, interventions, outcomes, and documentation. Managers need reliable and accurate data for resource allocation and management. The first step toward data standardization in order to facilitate, share, and compare it among different centers is the establishment of a minimum data set (MDS). MDS is a minimum set of agreed data elements collected at national or regional level and reported to related organizations. In this regard, the present study aims to investigate the role of the Alzheimer national registry system in the prevention treatment and management. The study was a narrative survey, which was done through searching in Google search engine as well as sites associated with Alzheimer with the help of some key words such as "minimum data set", "advantages", "treatment", "prevention" "Alzheimer", and "registry" in journal articles (abstracts and texts), books, conference abstracts, and other online documents from 2006 to 2015. Approximately, 70 articles, books, theses, and conference abstracts were obtained of which 50 cases were selected. Designing and development of MDS for Alzheimer seems necessary at the national level in Iran, so that data collection and analysis can help in designing of preventive programs.

**Keywords:** Senility; Alzheimer; Data set; Registry

## Introduction

Iran, which had faced young population growth in the last two decades is now experiencing elderly population growth. Alzheimer is a kind of brain disorder which almost affects elderly population. In this disease damage and death of brain cells leads to dysfunction of memory, thought, judgment, language, and other nervous activities which subsequently change individual behavior and personality. According to Iran's Alzheimer Association, more than 26 million people suffer this problem across the world. World Alzheimer's Association said in every four seconds someone in the world and in every 7 minutes a person is affected in Alzheimer's disease. Alzheimer begins with weakness in short term memory and ends in gradual forgetting of everything, even the person's identity. Based on statistics of 2012, every four seconds, one person in the world suffers this disease. The Progressive trend of the disease as well as lack of certain treatment for it has changed Alzheimer into one of important mortality factors in the world. The number of people who suffer Alzheimer was more than 75 million in 2012 and it is predicted that the number will be two times until 2050 [1-3].

Alzheimer is a great burden for the community. Its unfavorable outcomes which are usually disastrous lead to higher healthcare expenses and bring emotional challenges for patients' relatives with subsequent mental as well as spiritual damages for involved families. These outcomes are sometimes so wide and painful that can affect active and productive sections of the society seriously and incur high expenses on the communities. For every individual affected by Alzheimer at least three people are directly involved with disease outcomes as care givers. According to studies done in this regard, the number of Alzheimer patients in developing countries is increasing faster than industrial and developed countries the reason of which may be due to the growth of health indices and increased life span. Old age is known as one of the important factors of this disease. A comprehensive report by world health organization (W.H.O) in 2010 indicated the requirement of consistent planning and conscious reaction of governments and different sectors to deal with this problem, particularly in low- or medium-income communities. According to the same report, the number of patients suffering dementia was 6.35 million in 2010 and it is estimated that every year, 7.7 million new cases will be added to this number. High expenses of this disease can be a basic challenge for healthcare system of countries. The above report has estimated the costs of the disease over 604 milliard dollars every year which is expected to increase over the predicted amount due to the increasing number of patients. These factors, along with increasing life span necessitate a wider look in dimensions beyond healthcare and medical issues. Alzheimer is progressing and statistics indicate that a little more than 8 percent of the country's population consists of elderly people. Iran faced burst of young population growth in less than two decades and is now experiencing old age generation along with problems and expenses which can be overcome very hard [1-5].

According to statistics by the country's elderly council secretariat with emphasis on the fact that in a time period of five years from 2006 to 2011 the older population of the country has increased from 7.3 to 8.2 percent with over one million people, if this trend continues, in 2051 year there will be about 25 million old people; in other words, if the population of the country is 100 million, one person will be old out of every four people. This issue will be simultaneously true all over the world [3-5].

Standards of W.H.O for old age are divided into three classes, including young elders (60-75 years), average elders (75-90 years), and elders (over 90 years). Accordingly, societies in which the population of people over 60 years is 12% or 8% of the population is over 65 years will experience old age phenomenon. According to the statistics of the country's elderly council secretariat, now in some parts of Iran such as Gilan and South Khorasan the population over 65 years has exceeded 10%. This fast trend of old age in the country necessitates that all institutions and organizations are prepared to deal with the phenomenon with each other's coordination. Health, social, service, well-fare, cultural, and even legal institutions should be changed, improved, and enhanced according to this inevitable phenomenon [4,5].

Minimum Data Set (MDS) is a minimum set of agreed data elements which are collected at national or regional level, and required reports are prepared for associated organizations from them. MDS provides a tool for collection of key data elements as well as a map and image for disease perception which subsequently makes comparison of data possible at local, state, and national levels, while healthcare institutes are able to meet governmental requirements and internal needs of each institute and eventually help the medical community in the management of disease [6,7]. Collection of proper data and presence of sufficient information regarding the causes and factors of Alzheimer will help in preventive programs and treatment management. In this regard, the present study aims to investigate the role of the Alzheimer national registry system in the prevention and management of this disease. The aim was to express the role of Alzheimer disease national registry system in the management of this disease.

## Method

The study is a narrative survey, which was done through searching in Google search engine as well as sites associated with Alzheimer with the help of some key words such as "minimum data set", "advantages", "treatment", "prevention" "Alzheimer", and "registry" in journal articles (abstract and text), books, conference abstracts, and other online documents from 2006 to 2015 solar year. Approximately, 70 articles, books, theses, and conference abstracts were obtained of which 50 cases were selected based on their relation to the topic.

### Significance of the study

In the latest statement of the European Union Council special emphasis has been made on the collection and registration of high-quality data and active participation among commission members. Development of information about problems, needs, and healthcare services was also stressed out [8]. At present, about one-third of the countries across the world has no system for annual reporting of healthcare data and about half of the country has no facilities for collection of epidemiologic data at national level [9]. Therefore, establishment of disease registration system is an inevitable necessity [10]. The primary objective of registration is keeping computer or office files from all healthcare cases associated with a particular population in which patients' personal information, features of services provided, and clinical features are recorded [11]. These data are collected continuously from different sources after which they are completely analyzed in recording centers, so that required information is provided regarding temporal and spatial prevalence of diseases [12]. The importance and necessity of registration system was first introduced by the American National Academy in 1966 regarding trauma and it was developed in 1989. Improvement of quality and evaluation of trauma patients as well as development of scoring trauma measures were among the main objectives of this system [13,14]. Reduction of mortality due to diseases, improvement of healthcare quality, identification of disease factors, development of control programs, prevention, and reduction of economic-social costs due to disease are among other objectives of the system [14,15].

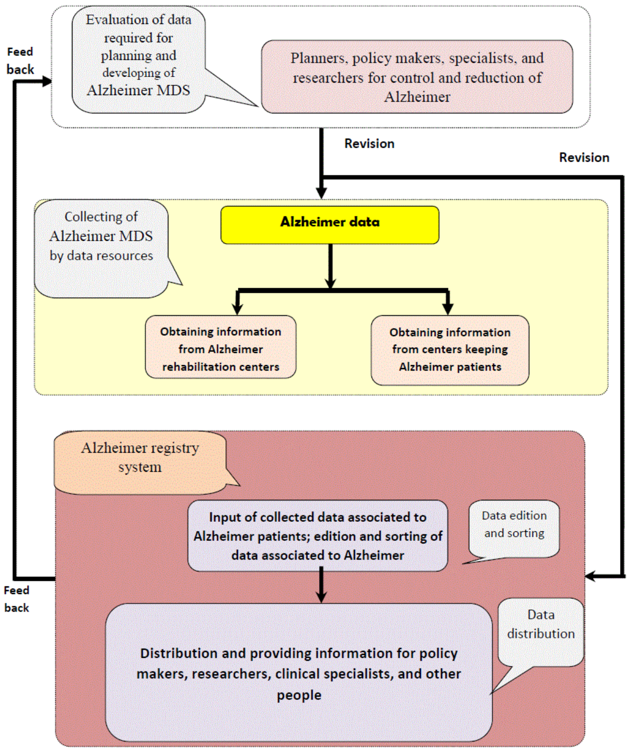

**Figure 1:** Conceptual map of the process and function of MDS in Alzheimer disease.

An information resource of disease registration system in Canada includes hospitals and state registration offices where information exchange takes place electronically. Demographic, diagnostic, and treatment actions information as well as data on mortality due to diseases are among the information gathered and analyzed in this system. In this system, only inpatient information was recorded and there was no outpatient information [15,16]. The disease registry system is a useful tool for monitoring the status of providing healthcare services according to healthcare service guidelines [6,8] while it is also a clinical tool for development of researches and a useful tool for data collection at all national and international levels [3,6]. The data registry system is a documented file which collects similar data systematically in order to provide scientific services or pre-determined policies [7].

Alzheimer can be investigated from different perspectives, including some cases such as high expenses of treatment, social and economic outcomes, causes of Alzheimer, and accelerating as well as influencing factors in the Alzheimer disease process (Figure 1). However, Alzheimer can be better discussed in a standard framework if there is a standard dataset for it. As a result, this issue has been considered here [17-20].

## Review of Previous Studies

### Advantages of using the national registry system

Registry system is an organized system for collection, registration, restoration, analysis, and distribution of information about people with special diseases. Moreover, registry systems are structured systems for collection and maintenance of information related to a defined population; this information is eventually investigated and analyzed (Figure 2). Use of this system is suitable for data collection, analysis, and also statistical studies [21,22].

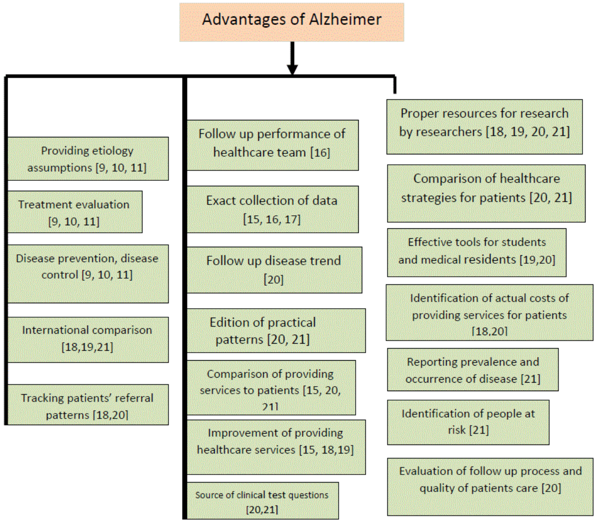

**Figure 2:** Advantages of Alzheimer MDS.

| **Organizational barriers** |
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| Organizational culture and attitude [20,22,23] |
| Lack of special procedures and policies for development of the registry system [23] |
| Lack of experienced and trained human resources [24,25]<br>Lack of required technical infrastructures for the establishment of the registry system [24,25] |
| Lack of experts' motivation for electronic communication due to lack of payment [20,25] |
| Lack of communication between healthcare institutes inside and outside the country [25] |
| Lack of experienced, trained, and suitable human resources for designing and developing health information management systems [13,14,18,19,22,26] |
| The resistance against change [24,27] |
| Lack of required technical infrastructures for the establishment of the registry system [20,24,25] |
| Lack of budget to support the development of health information management [13,14] |
| High expenses for tools and use of required technologies [19,26]<br>Requirement of sustainable support of expenses [19,26]<br>Investigation of financial, legal, cultural, technical, and managerial aspects [19,26] |
| Challenges in its use in disease management [19,22] |
| Requirement of investment for organization of a significant and compatible model for integration of information in health system. [13,14,19] |
| Requirement of prospective data collection and associated costs [13,26] |
| Technical limitations [13,14,18,19,22,26] |
| Lack of identification of data elements required for data collection and lack of information exchange standards [13,18,19] |
| Limitations in providing information based on predetermined MDS [13,19] |
| Contradictions and limitations due to interference with information systems [14,18,19] |
| Lack of communication between healthcare centers inside and outside the country [13,14,19] |

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| Time limitations [13,19,22] |
| Educational needs for information system usage [13,18,19,26] |
| Legal aspects [19,26] |
| Public concern regarding information security and confidentiality [13,17] |
| **Individual barriers** |
| Culture and attitude [13,14] |
| Lack of users' awareness about information technology and lack of trust to it [13,14,19] |
| Lack of experts' motivation to participate in electronic communication [13,19] |
| Resistance against change [13,14,18,19,22,26] |
| Lack of trust of healthcare providers [13,19] |
| Increasing healthcare providers given new processes such as interaction with patients, technology usage, and high volume of documents [13,19] |
| Unawareness of some users about skills required for data collection and associated processes [13,18,19,26] |
| Economic and social changes which lead to different levels of access to computer, internet, and education [13,19,22,26] |
| Registration of incomplete and wrong names in data sets [13,14,18,19,22,26] |
| A patient-based system is always exposed to risk because of potential access to incomplete or wrong data [19,22,26] |
| Most patients are illiterate and don't understand their disease conditions [14,22,26] |
| Some people's physical limitations in IT usage [13,14,19,22] |
| Organizational limitations and resistance against change [13,14,18,19,22,26] |
| Lack of sufficient studies regarding job turnover, perceived disease, information, registration, physical barriers, patients unawareness about outcomes of using this information [13,19] |
| Lacks awareness and support from internet and facing a large volume of different methods [13,19] |

**Table 1:** Individual and organizational barriers to registry systems.

Heyman et al. in an article titled "Cerebral Infarcts in Patients with Autopsy-Proven Alzheimer's Disease" stated that according to Alzheimer registry, patients who have a stroke are more exposed to Alzheimer disease" [19] (Table 1).

Fillenbaum et al. in an article titled "Progression of Alzheimer's Disease in Black and White Patients" stated that according of Alzheimer registry, skin color affects Alzheimer disease. Accordingly, prevalence of Alzheimer is 82% of white people and 66% of black people [19,24].

In a study by Mary titled "Communication Points for Providing Services to Alzheimer patients" it was stated that Alzheimer MDS can be a necessary tool for governmental states and federals stressing on the need to nursing centers for Alzheimer patients based on the increase in the number of patients; accordingly, Alzheimer MDS can play an intervention role as a key indicator in patients' treatment [24,25].

In a study done by Farmer et al. titled "EURO-WABB: an EU Rare Disease Registry for Wolfram Syndrome, Ahlstrom Syndrome, and Bardt-Biedl Syndrome" it was shown that use of information collected and registration can help in clinical management of diseases [27]. Moreover, it can help in identification of proper opportunities for interventions which delay disease progression [28].

Daneshvari et al. in an article titled "The NIH Office of Rare Disease Research Patient Registry Standard" stated that the registry for rare diseases can potentially reduce these diseases [28]. Not only registry system is useful for rare disease, but is can also affect the reduction of rare disease significantly.

Claudia et al. in a study titled "Cancer Prevalence in the City of Naples: Contribution of the GP Database Analyses to the Cancer Registries Network" in France indicated that the cancer registry system has a significant role in the reduction of costs and leads to planning for provision of acceptable services, while at the same time increases satisfaction in cancer patients [29,30].

Chul Park et al. in an article title "Characteristics and Survival of Korean Anal Cancer from the Korea Central Cancer Registry Data" in Korea stated that through the cancer registry system, the relationship between age and gender is determined in rectal cancer; this database is critically important for patients and plays a significant role in prevention of rectal cancer [30].

Johansson et al. in a study titled "Common Psychosocial Stressors in Middle-Aged Women Related to Long Standing Distress and Increased Risk of Alzheimer's Disease: A 38-Year Longitudinal Population Study" indicated that based on data collected, severe and long stress leads to Alzheimer [31].

Morris et al. in an article titled "Establishing a Trauma Registry in Bhutan: Needs and Process" stated that the collection of data and establishment of a national database can enhance services provided in areas related to trauma and medical emergencies [32,33].

Freshtehnejad et al. in an article titled "Comorbidity Profile in Dementia with Lewy Bodies Versus Alzheimer's Disease: A Linkage Study between the Swedish Dementia Registry and the Swedish National Patient Registry' indicated that according to the Alzheimer's registry, Alzheimer patients are exposed to neurological diseases, migraine, broke, eye diseases, respiratory diseases, diseases of genital urinary system, skin diseases, musculoskeletal diseases, and epithelium diseases [33].

Rick in an article titled Advantages of MDS for Diagnosis and treatment of Alzheimer patients" stated that Alzheimer's MDS leads to exact statistics about the number of Alzheimer patients and can eventually lead to awareness of responsible authorities regarding performing more studies and also enhancing the education of medical students toward better diagnosis and treatment [34].

Religa et al. in their study titled "SveDem, the Swedish Dementia Registry- a Tool for the Quality of Diagnosis, Treatment, and Care of Dementia Patients in Clinical Practice" stated that the data of 28722 Alzheimer patients at the age of 79 was registered in Sweden from 2007 to 2012 [35]. According to the results of this registration, it improves management of Alzheimer patients' care and also the process of diagnosis and treatment of these patients. The registry is fundamental to Alzheimer disease management.

Jonalit et al. in an article titled "Aging, Practice Effects, and Genetic Risk in the Wisconsin Registry for Alzheimer's Prevention" stated that according to a study done during the past five years, the number of Alzheimer patients is increasing and aging as well as genetic factors affect the development of this disease; accordingly, prognostic symptoms of disease should be identified in order to help early treatment [36]. Moreover, the sport has a significant effect on strengthening memory and reducing risk of Alzheimer.

Muller et al. in an article titled "Verbal Fluency and Early Memory Decline: Result from the Wisconsin Registry for Alzheimer's Prevention" according to Alzheimer registry, verbal speech is effective in prevention of Alzheimer diseases as well as memory decline; moreover, their results showed that family history of Alzheimer increases risk of this disease [37,38].

Jasmen et al. in their article titled "Surgical Outcomes of Hip and Knee Arthroplasties for Primary Osteoarthritis in Patients with Alzheimer's disease: a Nationwide Registry-Based Case-Controlled Study" suggested that according to the Alzheimer's registry, inpatient period, infection, and mortality are higher in patients suffering Alzheimer [38].

Falahati et al. in an article titled "The Use of MRI, CT, and Lumbar Puncture in Dementia Diagnostics: Data from the SveDem Registry" stated that according to the Alzheimer's registry, factors such as age and severity of cognitive disorders can significantly affect Alzheimer's disease and Alzheimer is diagnosed through diagnostic tests such as CT, LP, and MRI [20].

Karimi et al. in their research titled "Comparative Study of MDS of Organ Transplant Information Management System in Selected Countries and Providing Proper Strategies for Iran" stated that enhancement of quality of accessible information for decision making in healthcare is a national effort which should be concentrated on the effectiveness and efficiency of healthcare systems through the proper methodology of data collection and processing. MDS is considered the basis of obtaining effectiveness in healthcare as a proposed standard in data collection and processing [39,40].

In a study done by Arastoo et al. in 2012 titled "Standardization of Information Elements in Audiology File and Providing Proper Patterns for Iran" it was concluded that demographic minimum data sets, patients' history, evaluation of patients and treatment plan should be developed along with principles of designing medical forms and in the frame of audiology files for Iran [41].

In a study done by Tadayon in 2010 titled "Comparative Study of the National Registry for Acute Coronary Syndrome in Selected Countries and Providing Proper Strategies for Iran" it was stated that the basic aim of the registry is a data collection from health records and making them available for users. Collected data makes comparison, analysis, and study of patients possible. Therefore, this system can decrease the burden of cardiovascular disease and will have higher cost effectiveness for health centers in long term. Finally, in addition to the regular collection of data, other steps of the registry, including reporting collected data to national data management center, analysis of collected data, and distribution of information obtained through these analyses should be done systematically among the participating centers and other authorized users.

Hoseini et al. in their study titled "Designing MDS for Diabetes Mellitus: Diabetes Management Effectiveness Indicators" stated that correct and sufficient information about patients, time, site, and occurrence of the disease is an essential factor in prevention and control of every disease Which is in turn dependent on the management of patients' information [42].

Ahmadi et al. in their study titled "Data Elements of Nursing MDS" stated that given the importance of nursing data in providing health, establishment of NMDS is essential [43].

Sadughi in her study titled "Designing MDS Required in Iran Cancer Information Management" stated that national MDS is essential as the core of the national cancer control plan which can lead to better decisions at national level [44].

In a study done by Roshan-ghias et al. titled "Determining MDS of ICU in Educational Hospitals of Isfahan University of Medical Sciences in 2014 and Providing Solutions" stated that correct and sufficient information about patients, time, site, and occurrence of the disease is an essential factor in prevention and control of every disease, which is in turn dependent on the management of patients' information [45]. Identification of data elements required by ICU users can be the start of disease information management, while enhancement of care quality, disease control, and reduction of costs will result. Moreover, in this study it was concluded that some data elements of Intensive Care Unit (ICU) (burn, general, cardiovascular, and neonatal) which are currently used are not necessary and can be omitted. In addition, main data elements required by users in different wards of ICU were identified [46].

Ajami in a study titled "comparative study of iMed and MS European Database for Proposing a Common Language of Multiple Sclerosis Data Elements" concluded that "Data Sets" are the basic part of organizing information systems such as registration systems and structured medical records databases. Identification of essential data elements facilitates comparison and sharing of data between information systems. Organized collection and data integration can facilitate information' comparison and sharing, while disease management and research processes will be improved [47].

The results of studies regarding information registry systems in drug dependence treatment showed that this system can be considered as a minimum data set and help treatment personnel in drug dependence treatment through the provision of proper information according to users' needs. It can also help managers in planning, preventing, controlling, and treating programs through improvement of services provided and eventually help researchers in performing different studies [48,49].

Ajami et al. [49] in another study titled "comparative Study of Renal Diseases Registry System in America, England, and Iran" stated that Iran Nephrology society should play an active role in establishment of renal diseases national registry system. This system should have representatives from universities, government, armed forces, and private sector.

## Conclusion

Since information is the basic part of decision making, it is recommended to establish Alzheimer's disease national MDS in order to manage, control, and reduce this disease, so that preventive plans and programs can be provided after collection and analysis of data.

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