Review Article

# The role of information system in multiple sclerosis management

**Sima Ajami, Golchehreh Ahmadi[1], Masoud Etemadifar[2]**
Department of Management and Health Information Technology, Health Management and Economics Research Centre, [1]Department of Management and Health Information Technology, School of Medical Management and Information Sciences, [2]Department of Neurology, Director of MS Isfahan Clinic, Isfahan University of Medical Sciences, Isfahan, Iran

Multiple sclerosis (MS) is a chronic disease of central nervous system. The multiple sclerosis information system (MSIS), such as other information system (IS), depends on identification, collection and processing of data for producing useful information. Lack of the integrated IS for collecting standard data causes undesirable effects on exchanging, comparing, and managing. The aim of this study was to recognize the role of the IS in the MS management and determine the advantages and barriers in implementing of the MSIS. The present study was a nonsystematized review that was done in order to recognize the role of the IS in the MS management. In this study, electronic scientific resources such as scientific magazines and books and published topics at conferences were used. We used key words (IS, chronic disease management, and multiple sclerosis), their combination or their synonyms in title, key words, abstracts, and text of English articles and published reports from 1980 until 2013, and by using search engines such as Google, Google Scholar and scientific databases and electronic issues such as iPubMed, sufficiently important difference, Scopus, Medlib, and Magiran for gathering information. More than 200 articles and reports were collected and assessed and 139 of them. Findings showed that the MSIS can reduce of disease expenses through continuously collecting correct, accurate, sufficient, and timely patients and disease nature information; recoding; editing; processing; exchanging, and distributing among different health care centers. Although the MSIS has many advantages; but, we cannot ignore cultural, economic, technical, organizational, and managerial barriers. Therefore, it is necessary to do studies for preventing, reducing, and controlling them. One of the ways is to recognize the advantages of the MSIS and usage information technology in optimizing disease management.

**Key words:** Chronic disease management, database, data set, information system, minimum, multiple sclerosis, registry

**How to cite this article:** Ajami S, Ahmadi G, Etemadifar M. The role of information system in multiple sclerosis management. J Res Med Sci 2014;19:1175-84.

## INTRODUCTION

One of the biggest challenges, in the 21st century, is facing chronic disease that burdens heavy expenses on societies, for disease diagnosis, control and treatment and patients' hospitalization directly and indirectly.[1-5] Chronic diseases always allocate a considerable amount of health resources for themselves; because of need complex treatment and technologies and lack definite treatment. Hence, it is necessary to prioritize limited capitals and resources intelligently.[6]

Multiple sclerosis (MS) is a chronic disease of central nervous system[7,8] with unknown origin[9-11] that causes a widespread range of neurological manifestations and considerable disabilities.[12,13] MS attacks lead to increase disabilities and worst patient economic-social, clinical and physical situation.[14,15] About 2.5 million people suffer from this disease in the world.[16] It usually appears in 20-50 ages[17] and mostly in woman.[18,19] The MS is recognized as a second cause of disabling in the young population, after road accidents.[20] There are several hypotheses in pathogenesis of MS such as genetic and environmental factors.[21,22] The disease course is long, varied, and unpredictable[23-27] and it follows different patterns.[28] The MS geographical distribution is still indeterminate in spite of varied epidemiological studies during recent decades.[9] Varied reports from different areas of the world show that its prevalence and incidence is increasing especially in some area such as the middle east and Iran.[29-31]

Since, there isn't any complete treatment for the MS, present treatment focuses on prevention and management of disabilities.[32-36] The MS patients visit different clinicians during their treatment period. In visits, the patient plays a key role in exchanging information among providers. Many providers don't have enough information on the patient treatment history.[37-41]

**Address for correspondence:** Dr. Sima Ajami, Department of Management and Health Information Technology, Health Management and Economics Research Centre, School of Medical Management and Information Sciences, Isfahan University of Medical Sciences, Isfahan, P. O. Box 81745-346, Iran.
E-mail: ajami@mng.mui.ac.ir

**Received:** 14-09-2013; **Revised:** 18-11-2013; **Accepted:** 14-03-2014

There is not enough data on patients' care patterns.[20] Growth, development, and complexity environment have made health care organizations to look for more accurate and more information in order to achieve their efficiency and effectiveness and their survival in market.[42]

Nowadays information management system condition in most of developing countries is not encouraging.[43,44] To implement the information system (IS), all related and required patient information must be available.[45] Lack of methods and technologies for collecting national and standard data causes great gaps and suppress the ability in interchange data and also internal interoperability with other ISs.[46] Inappropriate information scattering makes undesirable effects on patients' future and preset care and so burdens more expenses on system.[47] Lack of integration among ISs is a barrier versus systematized analysis guidance on health system.[48] Data which is collected without structured contents doesn't promote knowledge level.[44,49] When data elements are gathered from different sources, they should be put under some regulations and standards for integrated maintenance.[50] Nature of chronic disease which needs information from several providers at the same time, and also a patient's need for accessing in his clinical information have made the creation of the integrated IS necessary.[51] The IS is an unavoidable necessity for huge investing and planning in order to quantitative and qualitative promotion of services offer, studying of services effectiveness amount in treatment performance, and making perseverance in case process. Experts believe that ISs in both health services management field and implementing care processes, make it possible to compare different course performance. This system plays an important role in effectiveness evaluation and appropriate decision making.[52,53] Moreover, implementing of a long-term multiple sclerosis information system (MSIS) recognizes inequality treatment and care in country level, and compare at worldwide.[54-72] Figure 1 shows the situation of the MSIS in the health system and its impacts on society.

The aim of this study was to recognize the role of the IS in MS management and determine present positive results and barriers in instituting of the MS integrated the IS.

## MATERIALS AND METHODS

The present study was a narrative review that was done in order to recognize the role of the IS in MS management. The study was done in a structured way and in three steps: Collecting, assessing, and choosing materials related to the aim. In this study, electronic scientific resources such as scientific magazines and books and published topics at conferences were used. We used key words (IS, chronic disease management [CDM], and MS), their combination or their synonyms in title, key words, abstracts, and text of English articles and published reports from 1980 to 2013, and by using search engines such as Google, Google Scholar and scientific databases and electronic issues such as iPubMed, sufficiently important difference, Scopus, Medlib, and Magiran for gathering information. More than 200 articles and reports were collected and assessed and 139 of them, which were related to the topic, were selected.

## RESULTS

Information management system programs start with data documentation.[73,74] The IS facilitates disease management by continuous collecting of timely, applied, sufficient, accurate and correct information on patients and disease nature and data updating.[75-78] The aim of the MSIS is to record, gather, process, assess, evaluate, exchange, and distribute data for decision making in health system.[79-84] In legal aspects view, the IS is a documented record on done procedures.[38]

Many studies indicate that basic steps to institute ISs are as follows [Figure 2]:

- Determining goals;[85,86]
- Guiding information management and executive teams;[43]
- Making involve the care providers for recognition of their information needs;[85]
- In determining policy and procedures;[43]
- Developing more information resources and infrastructures for achieving information details on disease progress and effective factors, in order to organize the IS and support clinical decisions and promote cares quality;[87]
- Developing executive tools and methods;[43]
- Determining standard data elements and developing MDS for data collection,[88-96] because data sharing among all of the care provider center is only possible through establishing and implementing a common language;[97-100]

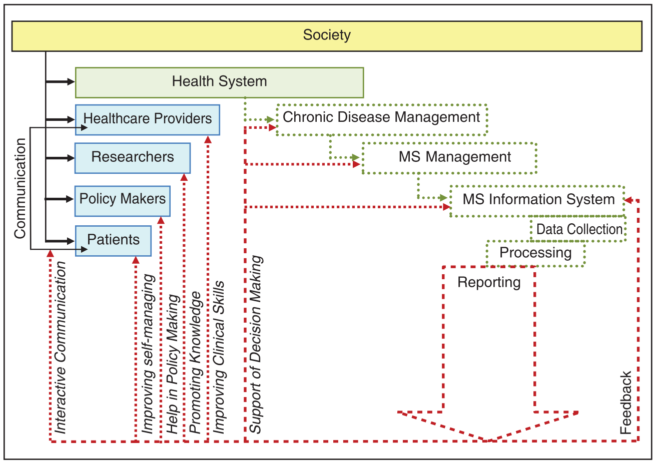

**Figure 1-GA:** Situation of the MS information system in the health system and impacts of it on society

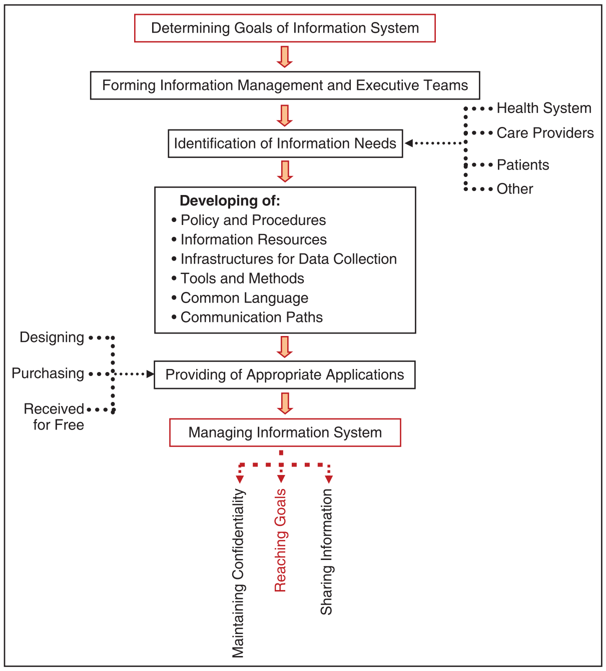

**Figure 2-GA:** Basic steps of instituting information systems

- Expanding coded and organized data communications;[101,102]
- Using applications in the IS which can be designed, purchased, and received free from some special organizations.[103]

It's possible to record in three places; home, clinic, and hospital. In order to care optimizing, these three places data should be integrated in the clinical record. The IS should collect data in three ways; through the internet and patients, disease management systems at a treatment institution level, and management data ordinary resources like primary care systems and/or hospital data; and it should make connections among data at the individual level.[22] Information gathering based on a patient's provided report on this situation, is useful for diseases such as MS. Thus, it is necessary to design a questionnaire and give it to patients. In this way, in addition to demographic, health care, disease situation, and disability situation, a widespread range of information related to MS patients' experiments, is collected. It is better to design a questionnaire, for receiving information from the patient, as "yes/no" checklists; so that analyzing of them would be easier.[24,82] Health system needs documentation of all patient care related data which is kept in a place and in a centralized way.[104-109] Thus, it's essential to have a central part in standard and integrated keeping and managing of other centers clinical information.[110]

For integrating of medical data in the patient record, it's necessary to institute standards, so that exchanging among independent computer applications and health systems is possible. Using data exchange standards and standard data definitions makes medical data sharing easier.[111,112] Standard documentation is an essential element in treatment consequences and disease course monitoring in MS patients.[113] By making a common language and integrating data we can present a unique definition on health, treatment and alarm situation,[67] although an amount of flexibility is necessary for the IS integration success.[50] Instituting essential standards for ISs as information management implementation infrastructure at every level of care is one of the most important roles of health information managers.[105] Information integration is necessary for continuous care, management, assessment, and quality improvement.[109]

A fundamental prerequisite for instituting the clinical information system (CIS) in CDM is network development and creation infrastructures and information technology.[104] Technology using in the IS will lead to develop information management systems and overcome present challenges; if there are enough researches and strategic perspectives for assuring its success.[114] Optimized using of information technology and efficient tools and electronic systems using for knowledge collection, organization, extraction, and sharing will lead to the patient's integrated medical information access and documentation improvement, treatment team communications improvement, error reduction, cares' quality improvement, expense reduction and reimbursements improvement, research facilitate and paper consumption reduction.[115-117] When paper medical records are without standard and specific structure, they will be inefficient in facing with information integration and different ISs.[51]

Information technology through automatic data recording increases accuracy, comprehensiveness and timeliness data by eliminating repetitive data entry.[118]

Through the integrated IS and optimum using of information technology,[119] in every place and at every time, users necessary information (managers, care and service providers, researchers and patients) will be achieved in an easy, fast, timely, and predetermined, appropriate to their knowledge and understanding and based on authorizing access range.[120]

Health information technology supports passing from institution-based on patient oriented and changes patient from a care services passive receiver to an active and determiner person in the treatment field. Patient oriented applications cause cooperation among treatment team, the patient and his family for ensuring procedures transaction and decision makings relevant to patients' needs.[104] One of the key goals in CDM is self-management encouraging in patients that will be possible by having a reliable IS, and promoting patient's awareness and knowledge of his situation, with the help of gathering information and development of patient and treatment team communication.[117] Self-management and lifestyle such as physical activity, healthy nutrition pattern and wrong habits leaving, are effective on chronic disease consequences.[36] People who have high ability in self-management can prevent from making many of their life-threatening complications.[121-125]

## Outcomes of instituting and implementing the integrated multiple sclerosis information system

### *For society*

- Estimating of disease prevalence and incidence and identifying of the MS geographical situation at country level;[11,22,89]
- Identifying of patient population characteristics;[25,119]
- Predicting of the patient's treatment need;[64,81]
- Logical and correct using of best present evidences in clinical decision makings;[126,127]
- Possibility of treatment adjustment with national and international developed instructions;[114,128]
- Reducing of probable errors due to information resource using with a smaller population;[106,129-131]
- Computing of useful life losing and disability years;[132,133]
- Reducing of death probability due to disease;[81]
- Social justice and equality and reducing of difference in methods;[54,128]
- Patients and treatment team satisfaction;[114,134]
- Ensuring of targeted using from present limited resources;[118]
- Controlling and reducing of expenses;[120,128]
- Identifying and surveying of risk factors;[77,89]
- Identifying people who are exposed to the risk of disease;[133]
- Providing of legal and management goals and informed guiding of policy makings and plans;[126,127]
- Making epidemiological studies targeted and encouraging of integrated and widespread researches in long term;[97,102]
- Exchanging and development of medical knowledge inside and outside of the country.[22,91]

### *For health providers*

- Monitoring of patients and following of disease progression in long-term;[122,123]
- Identifying and reporting of special cases in which disease management goals are not realized;[116]
- Describing of patients' care patterns and treatment plans;[99]
- Analyzing of patients' procedures consequences;[124,125]
- Possibility of data comparison;[97]
- Improving of interactive communications among treatment team and patients;[105]
- Preventing of repetitive works and reducing of extra procedures and examinations;[128]
- Identifying of requirements and using of technology for automated and systematized reminders and alerts.[78]

### *For patients*

- Continuously improving of disease prevention, control, and treatment and their complications quality;[128-133]
- Timely, continuous and efficient providing of care and services;[129,134]
- Supporting of collaborative treatment and harmonizing provided cares from different care providers and centers;[128]
- Encouraging of self-management and correcting of lifestyle by presenting evidences and educational resources;[135-137]
- Reducing of need to verbal visits and facilitating of internet counsel.[129]

## Barriers of instituting and implementing the integrated multiple sclerosis information system

Developing an information management system is not easy. The IS using barriers can be considered at two levels: Environmental and individual.[107]

### Environmental barriers

- Lack of organization's readiness for changing;[138]
- Little did researches regarding to change creation strategies and systems in organizations;[36]
- Lack of trained, qualified and appropriate human resources for designing and developing of health information management system;[43]
- Lack of organizational culture in which decisions should be based on the digits and facts;[43]
- Communication weakness among technology designers and sellers and health care and service providers and mangers;[138]
- Lack of chronic diseases management understanding and playing down population-based management;[36]
- Lack of understanding health information management role in organization management and limited use of data;[107]
- Unexpected consequences and workflow complexity;[71]
- There is always an argument for data controlling and ownership right because data is collected from different resources;[60]
- All of affective factors in disease course change creation are not controllable, generalizing of extract information from the IS is never discussed surely, and information which is extracted from the IS for biology mechanisms relation is not enough in advance new discoveries and future researchers;[24]
- Lack of investment for instituting change in organizations;[36]

- Lack of finance supporting for health information management development;[43]
- High expenses for necessary tools provision and technology usage;[117]
- In addition to primary expenses for infrastructures, purchasing and implementing, health information technology products need continuous expenses for supporting;[105]
- Evaluating financial, legal, cultural, technical, and managerial aspects of information technologies usage because there is not enough information about their effects according to present workflow and facilities;[139]
- Information technology usage challenges in disease management are discussed as technology complete acceptance barriers in health system;[71]
- Information integration in health system needs investment for instituting a significant and coherent model for information;[105]
- Necessity of data future gathering for necessary communications creation causes increasing expenses;[98]
- Technical;[59]
- Insufficiency of health information management system developing supporting policies;[36,43]
- Lack of health information technology infrastructures;[105]
- Not specified essential data elements for collection and lack of information exchange standards;[101]
- Limitation of present data based on predetermined MDS;[24]
- Present conceptual differences and defects in different resources data limit the possibility of the patient's situation monitoring and detection;[119]
- Information documentation which contains text writing, limits the possibility of searching;[60]
- Lack of unique identifying number of patients cause complexity and paying high expenses for information match at the individual level;[60]
- Inconsistency and limitations due to ISs contrasts;[98]
- Lack of treatment institution's communication inside and outside of the country;[100]
- Time limited;[107]
- Educational needs for the IS utilization;[138]
- Legal aspects;[59]
- Public worries about security and confidentiality.[105]

## Individual barriers

- Culture and attitude;[25]
- Users, awareness of information technology probable defects and so lack of stakeholders' trust and belief;[105]
- Lack of specialist' motivation for taking part in patient oriented communication specially electronic and internet-based, because it would be mostly virtual and without payment;[43]
- Resistances against change;[107]
- Care providers' overconfidence which prevents information sharing and interaction with patient in disease management and clinical decisions;[59]
- Increasing of health care and service provider's duty and work due to new processes such as interaction with patient, technology usage and high documentation volume;[36]
- All of users don't have information collection facilities, skill, and mood;[114]
- Social and economic variations cause difference in access to computer, internet, and education in these fields;[41]
- Incomplete recording and error and careless in data gathering;[24]
- When the IS is patient oriented, it will be always endangered by receiving incomplete or wrong information from patients which may lead to care provider's error in clinical decision makings and procedures transaction;[105]
- Patients' passive role in visits;[36]
- Many of the patients are illiterate in the health field and they don't have a correct understanding about their situation and disease;[105]
- Some people have physical limitations for using technologies;[59]
- Lack of the IS value understanding of patient;[138]
- Lack of awareness and health supports on the internet and/or immersed in a great volume of different methods;[135]
- Yet, it hasn't done enough study regarding patient's workflow out of the agency, patients' understanding and knowledge effect on disease and information recording, physical barriers, and patients' illiteracy in information using and consequences of its using;[59]
- All of these factors are overlapped, but it can be said that organization limitations and resistance against change, are the causes of other limitations and barriers.[107]

## Proposed solutions for opposing barriers of the integrated multiple sclerosis information system

- Encouraging of health system managers by saying the CIS implementation and creation, and information technology used in a way that it shows avoiding from expense waste, efficiency improve and output increase, and emphasizing on this note that efficiency increasing always lead to expense increases and complexity;[60]
- Understanding of the IS acceptance;[38]
- Making motivation for systematized activity in order to make positive changes and continuously improve of coarse quality;[25]
- Making cultural changes in specialists, so that it leads them to share patients' information;[95]
- Increasing in care providers' knowledge about new technologies and their usage in the IS;[71,129]

- Clear is defining and determining of data elements and terms in the IS in MDS format with the ability of updating and revising;[26]
- Utilizing of telemedicine ability and other information technology usages in health, from data gathering and archiving of information displaying and updating;[117,139]
- Integrating and organizing of information in one or more IS and information resources at the individual level, by determining the unique identifying number;[108]
- Facilitating of work so that users (doctor, nurse, researcher, etc.) by considering some standards, are able to enter and retrieve data;[35]
- Using of user friendly software with applied search possibility for selecting patients and doing evaluations and researches;[26,107]
- Avoiding of reparative recordings and lack of need to record data which is lateral product of other gathered data;[44]
- Complete and timely entered data;[60]
- Monitoring of data accuracy, consistency and quantity automatically or by neurologists, for minimizing missed or wrong data;[26,86]
- Maintaining of the IS by information important or apart supporting institutions;[97]
- Determining of information access range appropriate to stakeholders' role for confidentiality and security insurance;[4]
- Rich reporting work for replying to all users' needs;[38,60]
- Utilizing information technology in order to inform security presentation on the internet or network;[56,105]
- Making it possible to provide guidance and help from more experienced users to less experienced ones.[135]

## CONCLUSION

According to the done studies, we understood that the MSIS instituting and implementing has a lot of advantages. Collecting of accurate, correct, sufficient, and timely data on patient and disease nature will be possible, by making an integrated IS. The integrated IS causes that vital information, which are necessary for disease management, never be disregarded. The integrated IS will facilitate access to a scientific experiments and evidence-based system in order to make better decisions, more suitable treatment, suitable allocation of health care resources, exchange of different health care center's data, and reduction disease expenses.

Some of advantages in the MSIS are as follows:

- Following progress of disease;
- Monitoring treatment outcomes;
- Studying effective factors;
- Using evidence-based care programs;
- Supporting clinical decisions;
- Promoting teamwork and partnership in treatment;
- Increasing patients' awareness level;
- Encouraging self-management skills in patients;
- Expanding interactions and communications;
- Reducing disease expenses;
- Upgrading knowledge;
- Designing and implementing preventive procedures;
- Overcoming individual and environmental barriers;
- Controlling disease incidence.

In general, the MSIS is a useful and reliable tool in care improvement evaluation and it will be one of the vital prerequisite for electronic health record establishing in countries.

## ACKNOWLEDGMENT

This article resulted from part of a medical record education thesis and research project No. 392279 funded by the vice chancellor for research of the Faculty of Medical Management and Information Sciences, Isfahan University of Medical Sciences, Iran and our thanks them for their supporting.

## AUTHOR'S CONTRIBUTION

SA contributed in the conception and design of the work, drafting and revising the draft, approval of the final version of the manuscript, and agreed for all aspects of the work. GA contributed in the conception and design of the work, conducting the review study, drafting and revising the draft, approval of the final version of the manuscript, and agreed for all aspects of the work. ME contributed in revising the draft and agreed for all aspects of the work.

## REFERENCES

1. Karimi S, Javadi M, Jafarzadeh F. Economic burden and costs of chronic diseases in iran and the world. Health Inf Manage 2012;8:984-96.
2. Sahebalzamani M, Zamiri M, Rashvand F. The effects of self-care training on quality of life in patients with multiple sclerosis. Iran J Nurs Midwifery Res 2012;17:7-11.
3. Culpepper WJ 2nd, Cowper-Ripley D, Litt ER, McDowell TY, Hoffman PM. Using geographic information system tools to improve access to MS specialty care in Veterans Health Administration. J Rehabil Res Dev 2010;47:583-91.
4. Douglass D, Ramyasiri K. Regional chronic care management: Midland Region District Health Boards. 2008.
5. Ghazi-Saeed M, Meidani Z. Necessity of moving toward standardization in medical record departments. J Iran Med Rec Assoc 2005;1:13-9.
6. Yazdian G, Karimi I, Tofighi S. Comparative study of specified disease management and proposing a model for Iran. Res J Med Fac Shahid-Beheshti Univ Med Sci 2007;32:271.
7. Vasconcelos AG, Haase VG, Lima Ede P, Lana-Peixoto MA. Maintaining quality of life in multiple sclerosis: Fact, fiction, or limited reality? Arq Neuropsiquiatr 2010;68:726-30.
8. Hamdipour A, Osareh F. Scientometric study and visualization of multiple sclerosis-related publications during 1999-2008. Health Inf Manage 2011;8:649-661.

9. Etemadifar M, Janghorbani M, Shaygannejad V, Ashtari F. Prevalence of multiple sclerosis in Isfahan, Iran. Neuroepidemiology 2006;27:39-44.
10. Saadatnia M, Etemadifar M, Maghzi AH. Multiple sclerosis in Isfahan, Iran. Int Rev Neurobiol 2007;79:357-75.
11. Brønnum-Hansen H, Koch-Henriksen N, Stenager E. The Danish Multiple Sclerosis Registry. Scand J Public Health 2011;39:62-4.
12. Qutaishat FT. Information personalisation needs for people with multiple sclerosis: Implications and design guidelines. Eur J Soc Sci 2011;21:287-301.
13. Demaille-Wlodyka S, Donze C, Givron P, Gallien P, ETP Sofmer Group. Self care programs and multiple sclerosis: Physical therapeutics treatment - literature review. Ann Phys Rehabil Med 2011;54:109-28.
14. Buchanan RJ, Wang S, Huang C, Graber D. Profiles of nursing home residents with multiple sclerosis using the minimum data set. Mult Scler 2001;7:189-200.
15. Benito-León J, Morales JM, Rivera-Navarro J, Mitchell A. A review about the impact of multiple sclerosis on health-related quality of life. Disabil Rehabil 2003;25:1291-303.
16. Noseworthy JH, Lucchinetti C, Rodriguez M, Weinshenker BG. Multiple sclerosis. N Engl J Med 2000;343:938-52.
17. Wollin J, Dale H, Spencer N, Walsh A. The informational needs of the newly diagnosed person with multiple sclerosis and their family. Int J MS Care 2000;2:4.
18. Rudick RA, Cohen JA, Weinstock-Guttman B, Kinkel RP, Ransohoff RM. Management of multiple sclerosis. N Engl J Med 1997;337:1604-11.
19. Kalanie H, Gharagozli K, Kalanie AR. Multiple sclerosis: Report on 200 cases from Iran. Mult Scler 2003;9:36-8.
20. Flachenecker P, Stuke K, Elias W, Freidel M, Haas J, Pitschnau-Michel D, *et al*. Multiple sclerosis registry in Germany: Results of the extension phase 2005/2006. Dtsch Arztebl Int 2008;105:113-9.
21. Sampat MP, Berger AM, Healy BC, Hildenbrand P, Vass J, Meier DS, *et al*. Regional white matter atrophy — Based classification of multiple sclerosis in cross-sectional and longitudinal data. AJNR Am J Neuroradiol 2009;30:1731-9.
22. Ford DV, Jones KH, Middleton RM, Lockhart-Jones H, Maramba ID, Noble GJ, *et al*. The feasibility of collecting information from people with Multiple Sclerosis for the UK MS Register via a web portal: Characterising a cohort of people with MS. BMC Med Inform Decis Mak 2012;12:73.
23. Pette M, Zettl UK. The use of multiple sclerosis databases at neurological university hospitals in Germany. Mult Scler 2002;8:265-7.
24. Weinshenker BG. Databases in MS research: Pitfalls and promises. Mult Scler 1999;5:206-11.
25. Hatzakis MJ Jr, Allen C, Haselkorn M, Anderson SM, Nichol P, Lai C, *et al*. Use of medical informatics for management of multiple sclerosis using a chronic-care model. J Rehabil Res Dev 2006;43:1-16.
26. Trojano M, Paolicelli D, Lepore V, Fuiani A, Di Monte E, Pellegrini F, *et al*. Italian multiple sclerosis database network. Neurol Sci 2006;27 Suppl 5:S358-61.
27. Koch-Henriksen N, Brønnum-Hansen H, Stenager E. Underlying cause of death in Danish patients with multiple sclerosis: Results from the Danish Multiple Sclerosis Registry. J Neurol Neurosurg Psychiatry 1998;65:56-9.
28. Confavreux C, Vukusic S. Natural history of multiple sclerosis: A unifying concept. Brain 2006;129:606-16.
29. Etemadifar M, Maghzi AH. Sharp increase in the incidence and prevalence of multiple sclerosis in Isfahan, Iran. Mult Scler 2011;17:1022-7.
30. Etemadifar M, Abtahi SH. Multiple sclerosis in Isfahan, Iran: Past, Present and Future. Int J Prev Med 2012;3:301-2.
31. Chronic Disease Prevention and Management Strategy: Eastern Health. 2012.
32. Fouladi N, Salsali M, Ghofranipour F. Facilities and barriers agents for enhanced health in patients with chronic disease. Res Sci J Ardebil Univ Med Sci 2005;6:278-86.
33. Ghanati E, Hadiyan M, Daghighi-Asli A. Economic expenditures of multiple sclerosis medications and feasibility of providing health insurance policies for medications. J Health Adm 2011;14:37-54.
34. Northrop DE, Frankel D. Nursing home care of individuals with multiple sclerosis. New York: National Multiple Sclerosis Society; 2009.
35. Devonshire V. Clinical databases in MS: Patient management and research. Int MSJ 2001;8:56-66.
36. Glasgow RE, Hiss RG, Anderson RM, Friedman NM, Hayward RA, Marrero DG, *et al*. Report of the health care delivery work group: Behavioral research related to the establishment of a chronic disease model for diabetes care. Diabetes Care 2001;24:124-30.
37. Michel-Verkerke MB, Schuring RW, Spil TA. Workflow management for multiple sclerosis patients: IT and organization. Hawaii Int Conf Syst Sci 2004;6:60145.1.
38. Carbone D, Burgess S. Motivation for the adoption of chronic disease information systems in general practice. J Bus Syst Gov Ethics 2009;4:1-12.
39. Solomon MR. Information technology to support self-management in chronic care: A systematic review. Dis Manage Health Outcomes 2008;16:391-401.
40. Masoudi R, Mohammadi I, Ahmadi F, Hasanpour-Dehkordi A. The effect of self-care program education based on orem's theory on mental aspect of quality of life in multiple sclerosis patients. Nurs Iran 2009;22:53-64.
41. Miller DM, Moore SM, Fox RJ, Atreja A, Fu AZ, Lee JC, *et al*. Web-based self-management for patients with multiple sclerosis: A practical, randomized trial. Telemed J E Health 2011;17:5-13.
42. Frajzadegan Z, Javadi A, Asgari G, Manzouri L. Indicators of utilization as a means for assessment of health information management systems. Health Inf Manage 2007;4:23-31.
43. Wajid G, Al Zarouni AK, Al Massoud HA. Information Management as a Corner Stone for Improving the Quality of Healthcare Services in Pakistan. Pakistan: Pakistan Institute of Quality Control; 2002.
44. Miller K, MacCaull W. Toward web-based care flow management systems. J Emerg Technol Web Intell 2009;1:137-45.
45. Callaly T, Faulkner P, Hollis G, McIlroy D, Hantz P. The development of a mental health service patient information management system. Aust Health Rev 1998;21:182-93.
46. Karimi S, Saghaeian-Nejad-Isfahani S, Farzandipour M, Esmaeli-Ghayoumabadi M. Comparative study of minimum data sets of health information management of organ transplantation in selected countries and presenting appropriate solution for Iran. Health Inf Manage 2011;7:497-505.
47. Safdari R, Akbari M, Tofighi S, Moeinolghorabaii M, Karami G. Comparative study of clinical information systems of mental illness caused by the war in America, England and Australia and offer appropriate solutions for Iran. Res J Med Veteran 2009;2:44-9.
48. Mehrdad R. Health system in Iran. Jpn Med Assoc J 2009;52:69-73.
49. Rajab AA. A methodology for developing a nursing education minimum data set. Graduate School Theses and Dissertations by Scholar Commons. University of South Florida; 2005.
50. Sahay S, Monteiro E, Aanestad M, editors. Towards a political perspective of integrative research: The case of health information systems in India. The 9th International Conference on Social Implications of Computers in Developing Countries; 2007. São Paulo, Brazil.

51. Smith CA, Haque SN. Paper versus electronic documentation in complex chronic illness: A comparison. AMIA Annu Symp Proc 2006;2006:734-8.
52. Safdari R, Azad-Monjir Z. Survey of information management standards in commission on accreditation of rehabilitation facilities. J Paramed Fac Tehran Univ Med Sci 2008;3:18-29.
53. Farzi J, Salem-Safi P, Zohoor A, Ebadifard-Azar F. Survey of national diabetes registry system and presenting appropriate model for Iran. Ardebil Univ Med Sci Res J 2008;8:288-93.
54. Flachenecker P, Khil L, Bergmann S, Kowalewski M, Pascu I, Pérez-Miralles F, *et al*. Development and pilot phase of a European MS register. J Neurol 2010;257:1620-7.
55. Nolte E, Knai C, McKee M. Managing Chronic Conditions (Experience in 8 Countries). Denmark: European Observatory on Health Systems and Policies; 2008.
56. Green CJ, Fortin P, Maclure M, Macgregor A, Robinson S. Information system support as a critical success factor for chronic disease management: Necessary but not sufficient. Int J Med Inform 2006;75:818-28.
57. Nair BR, Finucane PM. Reforming medical education to enhance the management of chronic disease. Med J Aust 2003;179:257-9.
58. Infante F, Holton C, Powell-Davies G, Bubner T, Beilby J, Harris M. Organisational capacity and chronic disease care (an Australian general practice perspective). Aust Fam Physician 2007;36:286-8.
59. Lober WB, Zierler B, Herbaugh A, Shinstrom SE, Stolyar A, Kim EH, *et al*. Barriers to the use of a personal health record by an elderly population. AMIA Annu Symp Proc 2006:514-8.
60. Mittman R. Using clinical information technology in chronic disease care: Exper workshop summary. California HealthCare Foundation; 2004.
61. Flachenecker P, Stuke K. National MS registries. J Neurol 2008;255 Suppl 6:102-8.
62. Tremlett H, Zhao Y, Rieckmann P, Hutchinson M. New perspectives in the natural history of multiple sclerosis. Neurology 2010;74:2004-15.
63. Trojano M. Can databasing optimise patient care? J Neurol 2004;251 Suppl 5:V79-82.
64. Stuart L. Managing Chronic Conditions. USA: Family Health International; 2008.
65. Studney DR, Lubin FD, Marcucci L. MS COSTAR: A PC based medical information system to support and pool data among multiple sclerosis clinics. Proc Annu Comput Appl Med Care 1989; 13:943-4.
66. Hoseini A, Moghaddasi H, Naghavian M. Data elements used in dental care settingd in selected countries and designing a model for Iran. Health Inf Manage 2012;8:872-83.
67. Karami M, Setayesh-Barhaghi M. The role of data warehouse in optimizing diseases management. Health Inf Manage 2012;8: 97-106.
68. Rudge P. The value of natural history studies of multiple sclerosis. Oxford: University Press; 1999. p. 591-2.
69. Ajami S. Role of heroin addiction information management system for preventing and curing. J Homaye Salamat 2006;7:15-8.
70. Ajami S, Fatahi M. The role of earthquake information management systems (EIMSs) in reducing destruction: A comparative study of Japan, Turkey and Iran. Disaster Prevention and Management 2009;18:150-61.
71. Unertl KM, Weinger MB, Johnson KB, Lorenzi NM. Describing and modeling workflow and information flow in chronic disease care. J Am Med Inform Assoc 2009;16:826-36.
72. Elhadi M, Al-Hosni A, Day K, Al-Hamadani A, Al-Toqi A, Al- Shamli N, *et al*. Review of health information systems in Oman. Sultan Qaboos Univ J Sci 2007;12:101-20.
73. Nematollahi M, Khalesi N, Moghaddasi H. Comparative study of information HIV/AIDS management system in selected countries. Payesh 2012;11:425-33.
74. Stoops N, Williamson L, Heywood A, Hedberg C. Health Information Systems Programme (HISP) - The Success Story of a Development Project in South Africa. MEDINFO. 2001.
75. Rothman AA, Wagner EH. Chronic illness management: What is the role of primary care?. Ann Intern Med 2003;138:256-61.
76. Fard-Azar FE, Tofighi S, Bashardost N, Ajami S. A comparative survey on mortality information management systems in England, United States of America and New Zealand and proposing a suitable MIMS model for Iran. J Qazvin Univ Med Sci 2004;32:81-8.
77. Javadi M, Asgari H, Yaghoubi M, Tavazohi H. Self-assessment of noncommunicable disease care system at isfahan university of medical sciences. J Health Fac Health Res Inst 2009;8:47-60.
78. Cocosila M, Coursaris C, Yuan Y. M-healthcare for patient self-management: A case for diabetics. Int J Electron Healthc 2004;1: 221-41.
79. Lyons RA, Jones KH, John G, Brooks CJ, Verplancke JP, Ford DV, *et al*. The SAIL databank: Linking multiple health and social care datasets. BMC Med Inform Decis Mak 2009;9:3.
80. Ajami S, Ketabi S. Performance evaluation of medical records departments by analytical hierarchy process (AHP) approach in the selected hospitals in Isfahan : Medical records dep. & AHP. J Med Syst 2012;36:1165-71.
81. Hoseini A, Moghaddasi H, Jahanbakhsh M. Designing minimum data sets of diabetes mellitus: Basis of effectiveness indicators of diabetes management. Health Inf Manage 2010;7:340.
82. Vollmer TL, Ni W, Stanton S, Hadjimichael O. The NARCOMS patient registry: A resource for investigators. Int J MS Care 1999;1:12-5.
83. iMed: Electronic Multiple Sclerosis Patient Clinical Database User Manual. Germany: Merck Serano SA; 2010.
84. Nematollahi M, Hatam N. Designing a regional information system for surveillance of voluntary HIV/AIDS counselling and testing in Iran. Health Inf Manage 2011;8:594-600.
85. Flachenecker P, Zettle UK, Götze U, Hass J, Schimrigk S, Elias W, *et al*. MS-Register in Deutschland: 1. Design und erste Ergebnisse der Pilotphase. 2005.
86. Arts DG, de Keizer NF, de Jonge E. Data Quality Measurement and Assurance in Medical Registries. Amsterdam: MEDINFO; 2001.
87. Dennis M, Scott CK. Managing addiction as a chronic condition. Addict Sci Clin Pract 2007;4:56-7.
88. Laing K. Use of the SGNS minimum data set in the clinical area. Gastroenterol Nurs 2005;28:59-60.
89. Lotf-NeJad-Afshar H, Zareh-Fazlollahi Z, Khoshkalam M, Rezaei-Hacheso P. Comparative study of mental health registry system of United Kingdom, Malaysia and Iran. Health Inf Manage 2009;6:1-10.
90. Ghodse H, Jones M, Thorley A. The need for more comprehensive data on addicts. Psychiatr Bull 1994;18:169-70.
91. Kanter AS, Bukachic F, Johnson DE. Bridging Culture and Language: IPH Search - A Pilot Global Health Information System. Amsterdam: MEDINFO; 2001.
92. Nhampossa JL, Sahay S. Social Construction of Software Customization: The Case of Health Information Systems From Mozambique and India. 2005.
93. Gerritsen DL, Achterberg WP, Steverink N, Pot AM, Frijters DH, Ribbe MW. The MDS challenging behavior profile for long-term care. Aging Ment Health 2008;12:116-23.
94. Kossi EK, Sæbo JI, Titlestad OH, Tohouri RR, Braa J. Comparing strategies to integrate health information systems following a data warehouse approach in four countries. J Inf Technol Dev 2010.

95. Hampson JP, Roberts RI, Morgan DA. Shared care: A review of the literature. Fam Pract 1996;13:264-79.
96. Lynge E, Sandegaard JL, Rebolj M. The Danish National Patient Register. Scand J Public Health 2011;39:30-3.
97. Hyppönen H, Viitanen J, Reponen J, Doupi P, Jormanainen V, Lääveri T, *et al*. Large-scale eHealth Systems: Providing Information to Support Evidence-based Management. eTELEMED: The 3rd International Conference on eHealth, Telemedicine, and Social Medicine; 2011.
98. Treviño FM. Uniform minimum data sets: In search of demographic comparability. Am J Public Health 1988;78:126-7.
99. Lu DF, Street WN, Currim F, Hylock R, Delaney C. A data modelling process for decomposing healthcare patient data sets. Online J Nurs Inf 2009;13:1-26.
100. Hirdes J, Pearson B, Curtin-Telegdi N. Educational approached for the minimum data set series of instruments. Senior Care Canada; 2002.
101. National Institute of Biomedical Imaging and Bioengineering/National Heart, Lung, and Blood Institute/National Science Foundation Workshop Faculty, Price CP, Kricka LJ. Improving healthcare accessibility through point-of-care technologies. Clin Chem 2007;53:1665-75.
102. Ferreira M, Kowal P. A minimum data set on ageing and older persons in sub-Saharan Africa: Process and outcome. Afr Popul Stud 2006;21:19-36.
103. Metzger J. Using computerized registries in chronic disease care: Oakland, Calif, USA: California Health Care Foundation; 2004.
104. Demiris G, Afrin LB, Speedie S, Courtney KL, Sondhi M, Vimarlund V, *et al*. Patient-centered applications: Use of information technology to promote disease management and wellness. A white paper by the AMIA knowledge in motion working group. J Am Med Inform Assoc 2008;15:8-13.
105. Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: Transformative tools for consumer-centric care. BMC Med Inform Decis Mak 2008;8:45.
106. Cutter GR, Baier ML, Rudick RA, Cookfair DL, Fischer JS, Petkau J, *et al*. Development of a multiple sclerosis functional composite as a clinical trial outcome measure. Brain 1999;122 :871-82.
107. Boonstra A, Broekhuis M. Barriers to the acceptance of electronic medical records by physicians from systematic review to taxonomy and interventions. BMC Health Serv Res 2010;10:231.
108. Thygesen LC, Daasnes C, Thaulow I, Brønnum-Hansen H. Introduction to Danish (nationwide) registers on health and social issues: Structure, access, legislation, and archiving. Scand J Public Health 2011;39 7 Suppl:12-6.
109. Meidani Z, Safdari R, Farshid Far G, Lak-Bala P. Comparative survey of information management standars with approach of establishing electronic health record. Med J Hormozgan 2005;10:167-72.
110. Hajavi A, GholiPour L, Haghani H. Designing a health information management model of seniles centers in Iran. Health Manage Res Sci J 2005;9:29-38.
111. Hellwig K, Haghikia A, Rockhoff M, Gold R. Multiple sclerosis and pregnancy: Experiences from a nationwide database in Germany. Ther Adv Neurol Disord 2012;5:247-53.
112. Papais Alvarenga RM, Alves Leon S, Tilbery CP, Poser C, Miranda Santos CM. SIAPEM - Brazilian software database for multiple sclerosis research in tropical countries. 2003;22:(2): NP. Available from: http:// ajns.paans.org/article.php3?id_article=87. [Cited 2003 Apr 04]
113. Schröder M. MUSIS 2.0 - Multiple sclerosis information system: An easy-to-use-database to improve the care of patients with multiple sclerosis. Mult Scler 1999;5:299-301.
114. Mashamaite SS. The effects of an electronic medical record on patient management in selected human immunodeficiency virus clinics in Johannesburg. South Africa: University of South Africa; 2011.
115. Confavreux C, Compston DA, Hommes OR, McDonald WI, Thompson AJ. EDMUS, a European database for multiple sclerosis. J Neurol Neurosurg Psychiatry 1992;55:671-6.
116. Simon J, Powers M. Chronic Disease Registries: A Product Review. Oakland, Calif, USA: California Health Care Foundation; 2004.
117. Shea S. Health delivery system changes required when integrating telemedicine into existing treatment flows of information and patients. J Telemed Telecare 2006;12 Suppl 2:S85-90.
118. Masoudi-Asl I, Nasiripour AA, Esmaeillou Y. Relationship of using smart card and drug consumption management of MS specific patients. Iran J Mil Med 2012;13:229-33.
119. Palace J, Boggild M. The UK multiple sclerosis database. Mult Scler 1999;5:297-8.
120. Keyvanara M, Sadeghi M, Saghaeiannejad-Isfahani S. A comparative review of national registry systems of acute coronary syndrome in selective countries. Health Inf Manage 2012;9:172-9.
121. Heidarzadeh M, Atashpeikar S, Jalilazar T. Relationship between quality of life and self-care ability in patients receiving hemodialysis. Iran J Nurs Midwifery Res 2010;15:71-6.
122. Alroughan R, Butzkueven H, Boz C, Chapman J, Cristiano E, Grand'Maison F, *et al*. MSBase. Australia: The MSBase Foundation Ltd.; 2012.
123. Bandari DS, Vollmer TL, Khatri BO, Tyry T. Assessing quality of life in patients with multiple sclerosis. Int J MS Care 2010;12:34-41.
124. Ajami S, Ketabi S, Isfahani SS, Heidari A. Readiness assessment of electronic health records implementation. Acta Inform Med 2011;19:224-7.
125. Shin JH, Scherer Y. Advantages and disadvantages of using MDS data in nursing research. J Gerontol Nurs 2009;35:7-17.
126. Ford DV, Jones KH, Verplancke JP, Lyons RA, John G, Brown G, *et al*. The SAIL Databank: Building a national architecture for e-health research and evaluation. BMC Health Serv Res 2009;9:157.
127. Ajami S, Amini F. Evaluate the ability of clinical decision support systems (CDSSs) to improve clinical practice. Med Arh 2013;67: 126-30.
128. Ajami S, Bagheri-Tadi T. Barriers for Adopting Electronic Health Records (EHRs) by Physicians. Acta Inform Med 2013;21:129-34.
129. Kabiri P, Aminpour F. Ehealth: Strengths and weaknesses. J Iran Med Rec Assoc 2005;2:33-7.
130. Raban MZ, Dandona R, Dandona L. Availability of data for monitoring noncommunicable disease risk factors in India. Bull World Health Organ 2012;90:20-9.
131. Ajami S, Ketabi S, Yarmohammadian MH, Bagherian H. Wait time in emergency department (ED) processes. Med Arh 2012;66:53-7.
132. Safdari R, Masouri N, Aminian O, Davoudi S. Comparative study of goals and structure of occutational disease information system in selected countries. J Paramed Fac Tehran Univ Med Sci 2007;2:72-6.
133. Zohoor A, Asadi F. Suggesting a national trauma registry system for Iran. Iran Univ Med Sci J 2005;12:349-56.
134. Bates DW, Gawande AA. Improving safety with information technology. N Engl J Med 2003;348:2526-34.
135. Sheaves B, Jones RB, Williamson GR, Chauhan R. Phase 1 pilot study of e-mail support for people with long term conditions using the Internet. BMC Med Inform Decis Mak 2011;11:20.
136. Barrett M, Ben-Zacharia A, Blaschuk C, Costello K, Easterling C, Gutierrez A, *et al*. Nursing management of the patient with multiple sclerosis. USA: TEVA Neuroscience; 2011.
137. Busse R, Blümel M, Scheller-Kreinsen D, Zentner A. Tackling Chronic Disease in Europe (Strategies, Interventions and Challenges). Denmark: European Observatory on Health Systems and Policies; 2010.

138. Ajami S, Mohammadi-Bertiani Z. Training and its impact on hospital information SYSTEM (HIS) success. J Inf Technol Softw Eng 2012;2:112.
139. Hatzakis M Jr, Haselkorn J, Williams R, Turner A, Nichol P. Telemedicine and the delivery of health services to veterans with multiple sclerosis. J Rehabil Res Dev 2003;40:265-82.

**Source of Support:** This article resulted from part of a Medical Record Education thesis and research project No. 392279 funded by the vice chancellor for research of the Faculty of Medical Management and Information Sciences, Isfahan University of Medical Sciences, Iran. **Conflict of Interest:** None declared.