Provision of the minimum dataset of asthma for electronic health record

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ABSTRACT

Background: Determining the standard data elements for developing an integrated information system is of crucial importance in order to better design electronic health records system at the national level. The aim of the present study was to determine the minimum data elements of asthma for the electronic health record in Iran. Materials and Methods: The present study was an applied research that was conducted in a descriptive method. Minimum dataset (MDS) of asthma in selected countries was assessed through print and electronic literature. Data on MDS of asthma in selected countries were analyzed using comparative tables and determining the common and differentiating features of the dataset. At the validation phase of the model, frequency distribution (number and percentage), median, and quark distortion index of the questions in the questionnaire were analyzed using SPSS and Minitab software. Results: MDS of asthma was categorized into management and clinical classes. Management class had 3 subclasses (demographic, clearance, and insurance-financial) and 12 data elements, whereas clinical class had 4 subclasses (risk factors, diagnosis, treatment, and asthma education to the patient) and 22 data elements. Conclusion: The present study showed that some of the essential data elements in the MDS of other countries are needed by organizations or care providers in the country that were not collected. Therefore, a complete list of the minimum data elements set for the health electronic record was created.

Keywords: Asthma, electronic health record, minimum dataset

Introduction

Many data are produced in modern medicine, but there is always a wide gap between collection and interpretation of data. On the other hand, the available data are bulky and confusing. Minimum dataset (MDS) creates a standard method for collecting key data elements and makes it easier to understand and compare data. It also fulfills the state requirements and the internal needs of each institution and medical community.[¹,²] There are currently 300 million asthmatic patients worldwide, and it is estimated that 100 million people will be added to this number by 2025.[³] According to the official statistics provided by the Ministry of Health and Medical Education of Iran and published in 2015, the incidence of asthma is about 13.5% for those under the age of 18 years and about 7% for those aged over 18 years.[⁴]

By increasing the follow-up time in patients with asthma, the reports become very bulky, and the accuracy of data recorded in paper medical records is difficult to validate.[⁵] Therefore, the application of electronic records in the management of asthma by receiving, organizing, and analyzing data and finally monitoring the consequences of care is very beneficial.[⁶]

World Health Organization has called all the countries to cope with asthma.[⁷] In addition, care, management, and the establishment of asthma information system are the research priorities in this area. Unfortunately, collected data are often not
suitable for decision-making in many cases. The dispersion of information recorded in these systems, encountering a large amount of data, lack of timely access to essential information for health-care providers, poor documentation of the data, and the existence of duplicate data are some of the problems in the current information systems.

Further, due to lack of integration of information systems in the country, designing a better electronic health record system requires standard and key data to exchange with the system. Given the importance of structured reports as a fundamental part of the electronic health record, the need assessment of the data elements for asthma seems necessary to determine the minimum set of standard and pivotal data.

Materials and Methods

The present study was an applied research that was conducted in a descriptive manner in four stages. In the first stage, the status of the existing data registration on asthma in hospitals affiliated to three medical universities of Tehran, Iran, and Shahid Beheshti was evaluated using the questionnaires that were filled by asthma specialists and head nurses in the internal wards. In addition, using medical records of patients, the existing forms and documentation were assessed. The validity of the tool was confirmed by experts’ opinions, and its reliability was confirmed by retesting method.

In the second stage, MDS of asthma was evaluated in the United States, Australia, Scotland, and Ireland, since these countries excelled in the field of health, asthma research, and the design of MDS. Data were collected by studying electronic and paper literature.

In the third stage, in order to determine the minimum national asthma dataset for the electronic health record and using comparative tables and through examining common and differentiating features in the MDS of asthma, every element of data that exists in at least two or more of the selected countries was put in the proposed MDS. In addition, using Delphi technique, an open-ended questionnaire based on two management and clinical aspects was prepared and sent to the experts (Delphi first round) and ultimately was incorporated in the national MDS of asthma for the electronic health record.

The evaluation of the suggested model by the researcher was carried out in the fourth stage using the Delphi technique (second and third rounds). In this regard, a survey of 13 asthma and internal specialists as well as 12 experts in the field of health information management was performed.

Analysis of data for the evaluation of asthma MDS in selected countries was conducted using comparative tables and the common and differentiating features of the dataset. Then in the model evaluation stage, data were analyzed using SPSS (version 22-chicago) and Minitab software through frequency distribution (number and percentage, along with median and quark distortion index for each question in the questionnaire).

Results

Findings of the Delphi technique for providing a model for the minimum set of asthma data elements showed that out of 28 distributed questionnaires among participants, 25 of them were filled. In this study, 17% of participants were female and 83% were male. In terms of education, 30% were asthma specialists, 25% were internal medicine specialists, and 45% had PhDs in health information management. Regarding age, 9.5% were in the age range of 25–34 years, 72.5% aged between 35 and 44 years, and 18% aged above 45 years. In terms of work experience, 5.9% had 5 or below 5 years, 12.6% had 6–10 years, 15.1% had 11–15 years, 5.4% had 16–20 years, and 21% had more than 20 years of experience.

The status of asthma registration in Tehran’s hospitals indicated that there is currently no standard and uniform recording method for recording asthma data. In addition, by referring to Asthma Society of Iran, it was determined that there is only a list of individual information of asthma specialists and there are no guidelines for recording asthma patients’ data. At the stage of identifying elements of the minimum set of asthma data for the electronic health record in other countries, MDS of asthma in the United States, Australia, Scotland, and Ireland was collected reviewing print and electronic literature.

In order to determine the MDS of asthma for the electronic health record, after identifying MDS of asthma in the studied countries and examining the common and differentiating aspects of them, every data element that exists in at least two or more of the selected countries was put in the proposed MDS. In addition, after sending an open questionnaire based on management and clinical aspects and conducting a survey of experts in Delphi’s first round, the national model of MDS of asthma was prepared for the electronic health record [Table 1].

Finally, in order to evaluate the MDS of asthma for the electronic health record, national model of the MDS of asthma for the electronic health record in a questionnaire with closed questions in two phases of the Delphi technique (second and third rounds) was sent to the experts. The number of data elements in the final set for the management class was changed from 20 to 12 elements and from 30 to 22 elements in the clinical class. The management class includes demographic (patient identification number, number of admissions, date of admission, age, sex, and postal code of the patient), clearance (clearance date, duration of stay, and clearance status), and insurance-financial (the main insurer, the private insurer, and costs) subclasses. The clinical class includes subclasses of risk factors (the current state of smoking, the onset of smoking, the time from quitting smoking, and the alcohol consumption), diagnosis (shortness of breath, night-time awakening, wheezing, nasal polyps, mucosal ingestion,
Table 1: Minimum dataset of asthma for electronic health record

| Data class          | Subclass   | Data element                                      |
|---------------------|------------|---------------------------------------------------|
| Managerial          | Demographic| Patient identification number                     |
|                     |            | Number of admissions                               |
|                     |            | Admission date                                     |
|                     |            | Age                                                |
|                     |            | Sex                                                |
|                     |            | Race                                               |
|                     |            | Nationality                                        |
|                     |            | Country of residence                               |
|                     |            | The patient’s zip code                             |
|                     |            | Height                                             |
|                     |            | Weight                                             |
|                     | Clearance  | Clearance date                                     |
|                     |            | Staying time                                       |
|                     |            | Clearance status                                   |
|                     |            | Emergency visit in the last year                   |
|                     |            | General practitioner visits in the last year       |
| Insurance-financial |            | The main insurer                                   |
|                     |            | Private insurer                                    |
|                     |            | Costs                                              |
|                     |            | Claiming compensation from the employer            |
| Clinical            | Risk factors| The current state of smoking                       |
|                     |            | The onset of smoking                               |
|                     |            | Time from quitting smoking                         |
|                     |            | The presence of smokers in the patient’s family    |
|                     |            | Alcohol consumption status                         |
|                     |            | School days absent                                  |
| Diagnosis           |            | Shortness of breath during activity                |
|                     |            | Awakening with dyspnea                              |
|                     |            | Wheezing or chronic cough without infection        |
|                     |            | The presence of nasal polyps                       |
|                     |            | Swallowing mucus                                   |
|                     |            | Sinusitis                                          |
|                     |            | X-ray image indicating chest distension            |
|                     |            | Disability in daily activities                     |
|                     |            | BMI calculation                                     |
|                     |            | History of asthma                                  |
|                     |            | Asthma diagnostic codes                            |
|                     |            | Date of performing spirometry                      |
|                     |            | Spirometry codes                                   |
|                     |            | Date of conducting PEFR                            |
|                     |            | Codes of PEFR                                      |
|                     |            | Date of FEV                                        |
|                     |            | FEV codes                                           |
|                     |            | Previous spirometry results                        |
| Treatment           |            | Brand of therapeutic drugs                         |
|                     |            | The dosage forms of medication                     |
|                     |            | Dosage of medications                              |
| Asthma education to patient |            | Methods of using respiratory spray                 |
|                     |            | Measure the air flow velocity during inhalation    |
|                     |            | Ventilator management                              |

Discussion

Care providers need accurate and up-to-date information for their professional and specialized activities. In other words, information is required in health systems due to their impact on care and treatment and should be distributed appropriately among users. Therefore, improving the quality of available information for decision-making in health care is a national effort that has to be provided through the establishment of appropriate methodologies. In addition, data processing should be focused on the effectiveness and efficiency of health-care systems. MDS, as a standard for collecting and processing data, is considered the basis for achieving effectiveness in health care. Most data in the MDS consist of managerial and clinical parts. Managerial data are collected with the aim of identifying and communicating with patients and are considered as the necessary data for identification, recall, and follow-up of patients. In addition, it is fundamental in determining the size, distribution of age, and sex of patients as a basis for care and provision of services, determining the level of illness and death, and determining the amount of utilization of the services for future designing. It should be noted regarding clinical data that these data are obtained through the diagnosis and treatment processes. In fact, clinical data not only are the basis for the direct care of the patient but also contribute to the process of reimbursement, planning, and research in health care.

Collection of asthma data, as the first step in asthma information management, requires a database in the form of specific asthma elements which can be finally used to measure and analyze the activities performed for patients by processing multiple indexes that are obtained. The study of Minnard et al., which was conducted to enhance the control-based activities with the integration of knowledge tools into electronic health records, showed that the integrity of the asthma care plan could be successfully implemented in electronic health records systems and facilitate the monitoring of patients’ outcomes. Furthermore, using the terminology and definitions of standardized data is necessary for measuring the performance and monitoring of asthma.

Similarly, in another study by Minnard et al. to investigate the application of asthma electronic health record in primary care, it was discovered that there is a dearth of asthma data elements in the electronic health record. They suggested that MDS, standard terminology, and valid indicators can lead to better care and monitoring of the outcomes.

The results of this study revealed that regarding the managerial class of data, except race, ethnicity, country of residence, sinusitis, X-ray indicating chest distension, asthma history, asthma diagnostic codes, date of performing spirometry, Peak expiratory flow rate (PEFR), Forced expiratory volume (FEV), and previous spirometric results, and treatment (brand, dosage form, and dosage of medication), and also asthma education to the patient (methods for using respiratory spray) subclasses.
height and weight in the demographic subclass, emergency and general practitioner visits in the past year in the clearance subclass, and claiming compensation from the employer in the insurance-financial subclass, other data elements had a high mean score and participants chose them as MDS of asthma in the electronic health record.

Regarding the data elements of the clinical class, data on the presence of smokers in the patient’s family and absences from school in the risk factors subclass, Body mass index (BMI), codes for PEFR and FEV in the diagnostic subclass, and measuring air flow velocity during inhalation ventilator and management in the asthma education to patient subclass had no priority from the perspective of participants, whereas the rest of data elements were introduced for the MDS of asthma.

Finally, according to the participants’ opinion and their prioritization, MDS of asthma for electronic health record was provided in 2 classes, that is, managerial (with 3 subclasses of demographic, clearance, and insurance-financial; and 12 data elements) and clinical (with 4 subclasses of risk factors, diagnostic, treatment, and asthma education for the patient; and 22 data elements).

**Conclusion**

Based on the current study, accurate and adequate information about the patients that are afflicted with a disease along with its time, place, and how it occurs is an essential element in the prevention and control of any disease that relies on patient information management. Unfortunately, despite the high prevalence of asthma in Iran, it has not been well addressed. Design and implementation of the MDS of asthma in the electronic health record is the basis for asthma information management and leads to the promotion of the quality of care and control.

MDS of asthma as an information database in two main managerial and clinical classes, by providing continuous care for patients, establishing a relationship between care providers, and analyzing the effectiveness of care for asthma patients lowers asthma complications and death, provides and anticipates necessary services, and prevents and controls the diseases and its costs. Thus, MDS of asthma allows for the evaluation of the quality of asthma care and is the basis for the indicators of the effectiveness of the care process, the quality of the services provided, and the outcomes of asthma management.

**Acknowledgments**

This study is the result of the research project IUMS/SHMIS-1395/27804. Technology and Research Deputy of Iran University of Medical Sciences funded this research. Thus, the researcher appreciates the cooperation of asthma, internal, and health information management specialists in Tehran, Iran, and Shahid Beheshti medical universities.

**Financial support and sponsorship**

Nil.

**Conflicts of interest**

There are no conflicts of interest.

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