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Designing a Minimum Data Set for Major Thalassemia Patients: Towards Electronic Personal Health Record

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ABSTRACT

Introduction: In modern medicine, large amounts of data are produced. However, there is always a gap between their collection and their understanding and interpretation. In this way, minimal data sets are prepared. Thalassemia major is a chronic genetic disorder of the blood and the most common genetic disorder in the world. Thus, the purpose of this study was to define a set for personal health of patients with major thalassemia.

Methods: This present applied research was done descriptively in a cross-sectional manner by Delphi method. To determine the dataset, the manual health records of thalassemia major patients were first evaluated based on the standard paper forms of the Ministry of Health, and the data required were collected according to the checklist. The questionnaire was first reviewed by a team of six experts in the field. Its content validity was determined by the team and its reliability by Cronbach's alpha as 96%. Then, a researcher-made questionnaire was prepared and surveyed among 113 experts on blood and oncology specialists around the country (Iran).

Results: from the 126 information element data surveyed, 117 IEDs were identified as the main elements with the agreement of more than 75% in the range of high and very high, while nine elements with the agreement of less than 50% in the range of low and very low were excluded from the elements list of personal health records of thalassemia patients. The information element data with the agreement of 50 to 75 in the range of moderate to high was not found in the survey. Finally, the minimum data set of individual health records of patients with thalassemia major was provided in 9 groups of demographic information, health history information, assessment information, laboratory data, drug information, blood transfusion, physical examinations, immunization (vaccination) and dental care.

Conclusion: In this study, the data elements were defined for personal health record of thalassemia patients. These data elements are considered as an appropriate data set for inclusion in the manual systems and electronic medical records and based on the patients' needs can be changed to be used as a national document.

Keywords: Minimum Data Sets, Data Elements, Personal Health Record, Electronic Personal Health Record, Thalassemia

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Introduction

Thalassemia major is a chronic genetic disorder of the blood because of the lack of synthesis of one or more globin polypeptide chains transferred from generation to generation according to the rules of Mendelian genetics [1.2]. Patients are characterized by signs and symptoms of chronic and severe anemia, lack of appropriate growth, enlargement of the spleen and liver, bone diseases, especially noticeable changes in the head bones and persons associated with changes in appearance [3]. Thalassemia is the most common genetic disorder in the world [4].It is estimated that there are about 270 million carriers for major hemoglobin disorders in the world, and every year about 300 to 400 thousand children with types of anemia are born around the world [5]. Until a few years ago, these patients died in the second decade of their life. However, today, with advances in treatment, and particularly after the beginning of iron deregulation treatment, a great progress has occurred in treating these patients. Nowadays, with proper treatment, the relatively long lifetime can be expected of them [6]. Therefore, due to high significant advances in the medical science area, reduced mortality due to thalassemia and increased life expectancy of these patients, their quality of life is considered as one of the most important indicators of health care [7]. Recent advances in information and communication technology have made it possible for comprehensive tools development, which is considered to support greater participation of the consumer in the healthcare process [8]. The personal health record is one such tool [9]. Research has shown that a lot of vital treatment and patients' health information in medical records, which are produced and maintained by hospitals and health- treatment centers, are not recorded or even will be recorded wrongly or incompletely. With a personal health record and its information that is available by the person himself, in addition to the fact that he can monitor the recording of information, he can provide complete and useful information to health care providers in emergency situations to improve clinical decisions [10]. Today, the information in each country is considered as a part of that country's national reserves, and achieving them has turned into an international competitiveness issue in the global arena. Due to the explosion of information technology phenomenon and as a result of growing information technology and electronic and computer devices in the past decade, setting up systems for the production and management of information appears to be essential [11- 13]. The quality of a case (file) regarding studies, research, scientific, and statistical information is dependent on the quality of the contents contained in that are recorded by those who documented them. This quality is often expressed in terms of relevance, completeness, availability, timeliness, and readability. Therefore, health record documentation is an important legal and professional requirement for all health professionals, since appropriate documentation facilitates the exchange of patient information for all the members of the treatment team, which is crucial by itself to ensure all care provided to the patient. In addition, medical records can be used for research, qualitative evaluation, and forensic medical purposes [14]. In advanced medicine, large amounts of data are produced; however, there is always a deep gap between collecting them, their understanding, and interpretation. On the other hand, the available data are bulky and confusing. Thus, the minimum data sets are prepared, which is a method to collect key data elements and resolves the internal need of each institution and, finally, the medical community needs [15- 17].

These sets typically include key data elements related to the clinical situation, procedure, expertise, field or care process to provide a comprehensive overview of the relevant data elements. The availability of reliable data sets is essential for the provision of integrated health care. In information

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systems, using data sets, the quality of care measures, the possibility of sharing health information and the global introduction of electronic health records [15, 18-20] are improved. In a descriptive -comparative study, Rangraz suggested an initial model for Iran personal health record, in which the concepts, trustees and how to use personal health record are mentioned, but more details such dataset were not discussed [21]. In Iran, there is no minimum data set of thalassemia patients' health, and the data are collected in a scattered pattern in clinics and hospitals. Due to the lack of health datasets on patients with thalassemia major, the establishment of an indigenous and scientific data seems to be necessary. The aim of this study was to determine the data set of electronic personal health records system for patients with thalassemia in Iran.

Methods

The present study was an applied research that was done descriptively by Delphi method. In this research, to determine the data set of personal health records of patients with thalassemia, the manual health records of thalassemia major patients were first evaluated based on the standard paper forms of the Ministry of Health, and the data required were collected according to the checklist. Then, a researcher-made questionnaire, including demographic information, health history information, assessment information, laboratory data, drug information, blood transfusion, physical examinations, immunization (vaccination) and dental care was prepared and surveyed by using the Delphi method. The questionnaire was first reviewed by a 6-expert team, including a blood and oncology specialist, a statistician and epidemiologist, a health information management professional, a specialist in medical informatics, a master of medical records education, and a master of health information technology. Its content validity was determined by the team and its reliability by Cronbach's alpha as 96%. The questionnaire was then sent to 113 of Hematology and Oncology specialists inside the country. The sample size determination was done by Morgan table. The specialists were asked to rate their degree of agreement in relation to each of the elements in the form of five options from "Very high" to "Very low." An open question was put in the end so that they can write their comments and suggested elements. The questionnaire was sent by in-person delivery and via email. According to the pattern, their decision making about the elements was as follows: If 75% or more of the respondents have selected the options of "Very high" and "High" for an element, the element will be considered as the main element; if 50-75% of the respondents have selected the options of "Very high" and "High" for an element, the element will be regarded as a proposed element. If less than 50% of respondents have selected the options of "Very high" and "High" for an element, the element will be removed from the case. After completing the questionnaires by hematology and oncology specialist, the data were analyzed using SPSS software version 14.

Results

According to data sets obtained through scientific studies, articles, references, medical records and standard forms of Ministry of Health, the minimum datasets related to electronic personal health records of patients with thalassemia were provided in the form of a questionnaire to 113 Hematology and Oncology Specialists. Of 113 questionnaires sent, 110 cases were received.

According to Table 1, 87.4% of respondents were faculty members. Most doctors (80.9%) were working in private and organizational hospitals, and also, most respondents had 10-20 years of work experience (67.3%). Of the 126 information element data surveyed, 117 IEDs were identified as the main elements with the agreement of more than 75% in the range of high and very high, while nine elements with the agreement of less than 50% in the range of low and very low were excluded from the elements list of personal health records of thalassemia patients. The information element data with the agreement of 50% to 75% in the range of moderate to high was not found in the survey.

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Table 1. Demographic information about respondents on the dataset of electronic personal health records of patients with thalassemia

Profile		Frequency	Percentage
Being Faculty Member	Yes	95	86.4%
	No	15	13.6%
	Total	110	100%
Working in Private and/or Organizational Hospitals	Organizational	14	12.7%
	Private	7	6.4%
	Private and Organizational	89	80.9%
	Total	110	100%
Years of Experience	>10	20	18.2%
	10-20	74	67.3%
	<20	16	14.5%
	Total	110	100%

Table 2. Minimum data set of personal health records of patients with thalassemia major

Main information data elements	Details
Demographic information	Name & Family, father's name, gender, national code, date of birth, place of birth (province, city), level of education, marital status, employment status, occupation type, type of insurance, Social Security number, date of validity of the insurance, supplemental insurance status, type of supplemental insurance, date of validity of supplemental insurance, supplemental insurance number, registration number, address, contact number.
Health History	Age at disease diagnosis, age at first blood transfusion, drug allergies, family history of certain other diseases, history of surgery, date of surgery, reason for surgery.
General physical examinations	Weight, height, blood pressure, recording head position, head circumference, recording face status, recording eye status, record thyroid status, spleen size, recording skin condition, recording the genital area status.
Biochemical data	Fbs ،2hpp ،Bun ،Cr، Ca ،Ph ، Uric acid ،ALK.ph ، SGOT ،SGPT ،T.Bill ،D.Bill ،LDH ، Ferritin ،TG ،Cholestrol ،U/A ، .U/C
Hematological data	Hb, Hct, RBC count, WBC count, platelet, MCV, MCH, MCHC, RDW, PT ، PT.
Immunological data	HBsAG(E.C.L) ، ,HBSAB(E.C.L) HIV
Pharmaceutical data	Drug name, date of onset of drug use, frequency of drug use ,the dosage of drug use, drug use method, drug discontinuation time.
Blood transfusion data	Type of thalassemia, blood group, blood group subsidiary, history of blood transfusion, blood transfusion interval (d), blood volume requested at each injection, product type, reaction to blood transfusion, blood filtering condition, receiving drug during the transfusion.
Physical tests data	Test name, test date, doctor, test results, 6-month checkups, tests, and examinations of hepatitis, 6-month tests and examinations of liver function, 6-month tests and examinations of ferritin, annual checkups of heart consultation and echo, annual surveys of bone densitometry tests, MRI of the liver, MRI of the heart.
Vaccination	Vaccine name, vaccination date
Dental care	Examination date, dentist, lesion type, lesion site, treatment action name.

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Discussion

Modern medicine produces a lot of data. However, there is always a gap between their collection, understanding and interpretation. Thus, minimal data sets are prepared, which is a method of collecting key data elements and resolves the internal needs of each institution and, finally, the needs of the medical community [22].The aim of this study was to determine the data set for personal health record of patients with thalassemia major. In this research to determine the dataset of personal health records of patients with thalassemia, was surveyed among experts on blood and oncology specialists around the country (Iran).In the case of demographic information, all of the data elements except for the mother's name and the village of the place of birth were excluded from the study. In the case of health history information, all elements were selected as the main data elements. In the case of General physical examination information were all data element s except for recording the condition of the ear, recording the condition of the nose, recording the condition of the throat, and recording the condition of the hair, and these elements were excluded from the research. In the case of Physical tests data, all data element except the auditory, optometry and endocrine/internal consultation were selected and these elements were excluded from the research. All the data elements of the laboratory reports, drug treatments, blood transfusions, vaccination, and dentistry were selected as the main elements.

In a study in 2006 entitled as "A joint program to assess diabetes in Asia" conducted by Kuo et al., a web-based system was designed through which clinical and epidemiological data of patients with diabetes were collected. On this site, doctors used identification information such as name, surname, age, gender, address and postal code to identify patients. Clinical data obtained from routine surveys, results of clinical examinations, including blood lipid levels, blood glucose and glycosylated hemoglobin, pharmaceutical data, History of disease, history of development of other Diseases, eye health, foot and kidney function were also recorded in the System [23].The minimum data set of demographic information, health history information, clinical test information, are consistent with the results of the present study. In 2009, Mariel et al. conducted a study entitled as "A web-based guide to determine the amount of insulin injection for patients with diabetes. In the designed system, the data related to blood sugar levels were recorded on a daily basis. Along with the patients, identifying information, including name, surname, age, sex, nationality and marital status, some other data elements such as socioeconomic status and consumption of drugs or alcohol were recorded in the system [24]. The demographic data of current study are consistent with this study. In 2011, in a study entitled as "Using and evaluation of remote diagnosis of skin diseases in the Honduras areas", Biez et al. also used identity and clinical data elements, including patient identification number, sex, medical history and disease history, family history, allergies and medications being consumed, status of treatments done and images of skin lesion as the minimum information sent to the specialist in the remote diagnosis system of skin diseases. However, Biez did not make an informed survey from the specialist to determine the data items, but in this study, the physicians were surveyed to determine the required information [25]. In a study by Hasannejad entitled as "Developing a web-based system for management of type I diabetes by patient" in 2014, in the stage of needs assessment, a research her-made questionnaire was designed based on the extensive literature survey, which included 32 closed questions in five areas (personal details, identity information, clinical information, clinical examinations and capabilities of the system). The questionnaire was provided to 30 patients with type I diabetes referred to the endocrine clinic of Imam Hussein (AS) Hospital in Tehran and 15 endocrinologists working in centers affiliated to Shahid Beheshti University of Medical Sciences. In the section of identity information, the data elements such as name, surname, age, gender, height, weight and the person contact number were deemed necessary, while the elements of father's name, national ID, contact number of a relative of

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the pat8ient, and the patient address of residence were identified as unnecessary elements by the majority of participants in the study [26]. In this study, as in the present study, a survey was conducted to determine the minimum data set. The Elements of father's name, national code, patient's address were selected as the main data elements. In Abdolkhani study [14] entitled as "Comparative study of minimum data set of athletes' health records in selected countries and presenting a model for Iran" in 2014, the researcher's questionnaire was designed based on the different sites of Sports Medicine of America, Australia, Canada as well as the Olympics website, and domestic activities by referring to Federation of Sports Medicine of Islamic Republic of Iran and examining the clinical examination forms used by the Federation and study the standard forms for reporting injuries, health history, physical examinations and clinical forms of the mentioned three countries and examples of electronic personal health records. The questionnaire included 11 sections of demographic information, health history, general body examinations, reporting injuries, physical examinations, medication, surgeries, physical therapy, nutrition, dental care and vaccination. The questionnaire was provided to 50 available samples of specialists of sports medicine, sport injuries and corrective actions, health information management, medical informatics and medical records. The demographic information included name and surname, father's name, place of birth, marital status, national code, registration number, date of birth, sex, blood group, address and phone number, name of the federation and information elements, sports team name and the name of the club. In the section of information elements of the health history, the factors of drug allergies, taking medications, past medical history, surgical history and family history of certain diseases were identified as information elements of Electronic personal health record of athletes. In the section of general body examinations, the factors of cause for referring, history of current illness and recording cardiopulmonary, musculoskeletal, neurological, eye, ear, nose and throat, skin and lymph nodes status were diagnosed as the Electronic personal health record data elements of athletes. In the section of physical examination, the factors of test name, test date, test results and recommendations based on the test results were identified as Electronic personal health record data elements of the athletes. In the section of drug treatment, the factors of the drug name, date of commencement and cessation of drug use, drug dosage, cause of administration, frequency of drug use, adverse effects and interfering with certain medication or food, drug shelf-life in the body, and list of illicit drugs were identified as Electronic personal health record data elements of the athletes. In the section of dental care, the factors of type and location of the lesion and the treatment measure name were identified as Electronic personal health record data elements of the athletes. In the vaccination section, the factors of vaccine name, vaccination date, cause of injection and the injection site according to the most participants were identified Electronic personal health record data elements of the athletes [14]. In consistence with this study, the demographic, health history, general examinations, drug treatments, vaccination and dentistry data also were considered. Some of the limitations of this study were the incomplete medical record of some thalassemia patients and also the lack of some participating experts in the completion of the questionnaire.

Conclusion

Data elements defined for the personal health of thalassemia patients included nine population information groups, history, assessment information, laboratory data, drug information, blood transfusion, physical examination, vaccination and dental care, which is considered a suitable set for inclusion in manual systems and electronic medical documentation. Since this data set was presented in a survey of oncologists and hematologists throughout the country, it is recommended to study and exploit it. Based on your patient needs, the required changes can be made to use it as a national document.

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Conflict of interest

The authors declare that there is no conflict of interest.

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