

Minimum data set of personal health record for patients with chronic respiratory diseases

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ABSTRACT

Introduction: Chronic respiratory diseases are one of the four main groups of non-communicable diseases. People with these diseases need access to data to manage their disease and care plan. Personal health record (PHR) as a powerful health information technology tool can empower chronic patients to better manage their health status and become an active member of health care teams. This study is to determine the minimum data set (MDS) in personal health record for patients with chronic respiratory diseases.

Material and Methods: This present applied research was done descriptively by Delphi method. First, the data sets of chronic respiratory diseases were extracted using a literature review. Then, using a researcher-made questionnaire and based on Delphi technique in two phases, it was evaluated by 5 pulmonologists.

Results: The PHR data set for chronic respiratory diseases was classified into six categories, including physical examination and clinical observation, laboratory data, medications, specialized treatments, diagnostic procedures and vaccination. The 33 data element were identified as the main data elements with an agreement of more than 80% in the first phase of Delphi technique. Also, in the second phase, the four data elements proposed by the experts in the first phase were agreed upon above 80%.

Conclusion: Given the role of PHR data in tracking the progress of chronic diseases, treating, and teamwork by physicians and other care providers, determining the minimum data set will be an effective step toward integrating and improving information management in these patients.

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INTRODUCTION

Chronic diseases are the leading cause of death in the world and about 71% of all deaths are due to these diseases [1]. The World Health Organization has stated that by 2030 deaths from chronic diseases will increase from 38 million to 52 million [2, 3].

Chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) are one of the four main groups of chronic diseases in which 4.1 million people die every year due to the disease [1, 4]. The increasing prevalence and incidence of these chronic diseases has created serious challenges for public health in the world and has reduced the quality of life and longevity of patients, reduced productivity and increased costs of health care

systems [5, 6]. Information and communication technologies in the field of health with a set of tools can facilitate overcoming these challenges [7].

Personal health records are a powerful health information technology tool that can empower chronic patients to better manage their health status and become an active member of health care teams [8, 9]. Electronic personal health records potentially and well play a supportive role in chronic disease self-management and can be used effectively to manage chronic diseases and communicate with the delivery team [10].

This file is an electronic file of people's health information through which people can access, manage, track and share their health data, and

authorized people can in a safe, confidential and secure environment. Patient privacy to access this data [11-13].

Designing electronic records requires a standard set of accurate and interchangeable data and information that is a prerequisite for providing optimal health care. Scattered information has adverse effects on patients' current and future health care and therefore imposes high costs on health care systems [14]. Minimal Data Set (MDS) creates a standard way to collect key data elements and make them easier to understand. It also provides important resources for treatment planning and continuous evaluation of progress and performance. In addition, it provides useful information for health care professionals, stakeholders and policy makers, and improves the quality of patient care and services [15].

Given the growing trend of chronic respiratory diseases and the socio-economic burden of these diseases and the loss of health costs [3, 16], self-care and patient participation in the care of chronic diseases by empowering these patients is very important. Also, despite the role of PHR data in patient data management, patient participation in care and empowerment in disease management, the researcher decided to design a minimum set of personal health records for chronic respiratory diseases.

MATERIAL AND METHODS

The present study is an applied study and aims to identify the minimum set of personal health records for chronic respiratory diseases. By reviewing texts including library resources, articles published in domestic and foreign journals, scientific documents, references to databases including PubMed, Scopus, Web of Science, Embase and reputable sites including the American Health Information Management Association, the organization World Health, Centers for Disease Control and Prevention (CDC) PHR datasets for chronic respiratory diseases were identified. Based on the extracted data set, a questionnaire was designed by researchers. The validity of the questionnaire was obtained through content validity based on the opinions of 5 experts in the field of health information management and medical informatics who had at least 5 years of educational and research experience.

In the relevant questionnaire, data elements in 6 categories including physical examination and clinical observation data (8 data elements), laboratory data (3 data elements), pharmacotherapy (6 data elements), specialized treatments (5 data elements), diagnostic measures (9 elements) and vaccination (2 data elements) were classified.

The answers to the questions were designed in two options, "for" and "against", and at the end of each

question, open-ended questions were provided to express other cases and corrective opinions of the respondents. The stage was provided to 5 respiratory specialists and in the first stage, Delphi technique, after collecting the questionnaires, the data were analyzed using descriptive statistics (number and frequency percentage) in Excel software. The data element in the Delphi technique steps was such that the data element, which was less than 50% by consensus of the experts, was removed, and the items that were approved by consensus by more than 75% were removed from the final list of minimum data sets. The PHR of chronic diseases remained, cases where the consensus reached between 50 and 75% was considered in the next stage, as well as new cases suggested by experts in the second stage of the Delphi technique questionnaire.

RESULTS

The minimum PHR data set of chronic respiratory diseases after reviewing the texts were classified into 6 categories with 33 data elements, which included the following:

Physical examination data and clinical observations: Shortness of breath during activity, shortness of breath, wheezing, cough, inability to perform daily activities, increased sputum production, pain or chest tightness, tachycardia.

- Diagnostic measures: Chest radiography, spirometry, bronchoscopy, plethysmography (body box), oscillometer (IOS), pulse oximetry, ventilation-transmission scan (profusion-ventilation scan), CT scan of the lungs, methacholine test.
- Laboratory data: complete blood cell count, arterial blood gas analysis, sputum culture.
- Specialized therapies: oxygen therapy, secretion suction, thoracostomy, ventilator use, lung rehabilitation (exercise, physiotherapy).
- Medication: Bronchodilators (beta agonists, anticholinergics, methyl xanthine), anti-inflammatory drugs (corticosteroids), H2 blocker, leukotriene interfaces, antacids, proton pump inhibitors.
- Vaccination: Influenza vaccine, pneumococcal polysaccharide vaccine.

The findings of the first phase of the Delphi technique according to Table 1 showed that the proposals related to the minimum PHR data set of chronic respiratory diseases were approved by experts with an agreement of over 80%. Sputum culture data element from laboratory data category, H2 blocker, leukotriene interfaces, and proton pump inhibitors

from pharmacotherapy category with 80% agreement scored lower than other data elements.

In the first phase, Delphi technique, daily sputum volume and nature and color of sputum were proposed for physical examination and clinical observation data, Alpha-1 Antitrypsin (AAT) for

laboratory data and ICS (inhaled corticosteroid) for pharmacotherapy data. According to Table 2, all elements of specialized data proposed by experts in the first stage of the Delphi technique for personal health records of chronic respiratory diseases with an agreement of over 80%, in the second stage of the Delphi technique were agreed upon by experts.

Table 1: Frequency distribution of experts' opinions about the minimum data set of personal health records of chronic respiratory diseases (first round of Delphi technique)

Category	Date Elements		Experts' ideas			
			Agree		Disagree	
			N	%	N	%
Physical examination data and clinical observations	Shortness of breath during activity		5	100	0	0
	Shortness of breath		5	100	0	0
	Chest tightness		5	100	0	0
	Cough		5	100	0	0
	Inability to perform daily activities		5	100	0	0
	Increased sputum production		5	100	0	0
	Pain or feeling of pressure in the chest		5	100	0	0
	Tachycardia		5	100	0	0
Laboratory data	Complete blood cell count or CBC		5	100	0	0
	Arterial blood gas analysis		5	100	0	0
	Cultivation of sputum		4	80	1	20
Pharmacotherapy	Bronchodilator	Beta agonists	5	100	0	0
		Anticholinergics	5	100	0	0
		Methyl xanthine	5	100	0	0
	Anti-inflammatory drugs (corticosteroids)		5	100	0	0
	H2 Blocker		4	80	1	20
	Leukotriene interfaces		5	100	0	0
	Antacids		4	80	1	20
	Proton pump inhibitors		4	80	1	20
Specialized treatments	Oxygen therapy		5	100	0	0
	Secretion suction		5	100	0	0
	Thoracostomy		5	100	0	0
	Use a ventilator		5	100	0	0
	Lung Rehabilitation (Exercise, Physiotherapy)		5	100	0	0
Diagnostic measures	Chest radiography		5	100	0	0
	Spirometry (performing lung function tests)		5	100	0	0
	Plethysmography (body box)		5	100	0	0
	Bronchoscopy		5	100	0	0
	Osilometry (IOS)		5	100	0	0
	Pulse oximetry		5	100	0	0
	Ventilation-transmission scan (perfusion-ventilation scan)		5	100	0	0
	CT Scan		5	100	0	0
	Methacholine test		5	100	0	0
vaccination	influenza vaccine		5	100	0	0
	Pneumococcal polysaccharide vaccine		5	100	0	0

Table 2: Frequency distribution of experts' opinions about the minimum data set of personal health records of chronic respiratory diseases (second round of Delphi technique)

Category	Date Elements	Experts' ideas			
		Agree		disagree	
		N	%	N	%
Physical examination data and clinical observations	Daily sputum volume	5	100	0	0
	Nature and color of sputum	5	100	0	0
Laboratory data	Alpha-1 Antitrypsin (AAT)	4	80	1	20
Pharmacotherapy	ICS (inhaled corticosteroids)	5	100	0	0

DISCUSSION

Health care data are valuable resources that are useful for managing and planning a person's entire life history in the treatment setting [17]. Designing disease data elements facilitates continuous, accurate, and complete documentation of patient information using standard terms to describe interventions and diseases [18]. The National Health Information Technology Association of America states that since the long-term goal of PHR is to create a lifelong source of appropriate information for individuals, the depth and breadth of information in PHR should be considered to empower individuals in their health care [19]. PHR data elements can be useful for population-wide disease tracking, quality control, and marketing [20]. In relation to chronic respiratory diseases data, in this study, 37 data elements in 6 categories were agreed as the minimum set of personal health records for chronic respiratory diseases.

For COPD, 8 data sets were reported as the minimum data set by Zarowitz et al. Only three categories of diagnoses, health status, and specific treatments included specialized data for the disease [21]. At present, these three groups were agreed upon by experts.

American Academy of Pediatrics 13 specialized data elements including Asthma Severity Score, Asthma Severity Score Measurement Date, Controlling Drugs, Controlling Medication History, Reliever Drugs, Reliever Drug History, Other Related Drugs, Comorbidities, Care Plan, Delivery Date Care plan, the date of the last maximum expiratory airflow, the result of the last maximum expiratory airflow, the date of the last spirometry have been introduced as data elements of asthma [22]. Some of these elements that were common in chronic respiratory diseases were considered as essential data elements in the

present study.

Sadoughi et al. Also stated the four main groups of data related to diagnosis, treatment risk factors, treatments and education to respiratory patients as the minimum set of electronic health record data [23]. The items mentioned in this study are consistent with the elements discussed in the present study.

Also, in the above studies, the data elements of daily sputum volume, nature and color of sputum, Alpha-1 Antitrypsin (AAT) test, influenza vaccine and pneumococcal polysaccharide vaccine were not mentioned, but in this study, they were suggested and agreed by experts.

CONCLUSION

By designing the minimum PHR data set for chronic respiratory diseases, a standard and structured MDS was provided accurately, completely and timely document the data of these patients. Determining this data set will be an effective step to integrate and improve the information management of these patients to track the course of chronic diseases, treatment and team approach by physicians and other care providers.

AUTHOR'S CONTRIBUTION

All authors contributed to the literature review, design, data collection and analysis, drafting the manuscript, read and approved the final manuscript.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest regarding the publication of this study.

FINANCIAL DISCLOSURE

No financial interests related to the material of this manuscript have been declared.

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