

عنوان مقاله:

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

محل انتشار:

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خلاصه مقاله:

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 was 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 dataset 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.

کلمات کلیدی:

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