Case Report

Healthc Inform Res. 2014 April;20(2):145-151.
http://dx.doi.org/10.4258/hir.2014.20.2.145
pISSN 2093-3681 • eISSN 2093-369X

HIR
Healthcare Informatics Research

DialysisNet: Application for Integrating and Management Data Sources of Hemodialysis Information by Continuity of Care Record

Ho Suk Ku, MD, MS[1], Sungho Kim, BS[2,3], HyeHyeon Kim, MS[2,3], Hee-Joon Chung, MS[2,3], Yu Rang Park, PhD[4], Ju Han Kim, MD, PhD[2,3]

[1]Departement of Internal Medicine, Inje University Seoul Paik Hospital, Seoul; [2]Seoul National University Biomedical Informatics (SNUBI), Seoul National University College of Medicine, Seoul; [3]Systems Biomedical Informatics Research Center, Seoul National University, Seoul; [4]Department of Biomedical Informatics, Asan Medical Center, Seoul, Korea

Objectives: Health Avatar Beans was for the management of chronic kidney disease and end-stage renal disease (ESRD). This article is about the DialysisNet system in Health Avatar Beans for the seamless management of ESRD based on the personal health record. **Methods:** For hemodialysis data modeling, we identified common data elements for hemodialysis information (CDEHI). We used ASTM continuity of care record (CCR) and ISO/IEC 11179 for the compliance method with a standard model for the CDEHI. According to the contents of the ASTM CCR, we mapped the CDHEI to the contents and created the metadata from that. It was transformed and parsed into the database and verified according to the ASTM CCR/XML schema definition (XSD). DialysisNet was created as an iPad application. The contents of the CDEHI were categorized for effective management. For the evaluation of information transfer, we used CarePlatform, which was developed for data access. The metadata of CDEHI in DialysisNet was exchanged by the CarePlatform with semantic interoperability. **Results:** The CDEHI was separated into a content list for individual patient data, a contents list for hemodialysis center data, consultation and transfer form, and clinical decision support data. After matching to the CCR, the CDEHI was transformed to metadata, and it was transformed to XML and proven according to the ASTM CCR/XSD. DialysisNet has specific consideration of visualization, graphics, images, statistics, and database. **Conclusions:** We created the DialysisNet application, which can integrate and manage data sources for hemodialysis information based on CCR standards.

Keywords: Renal Dialysis, Personal Health Records, Theraphy, Chronic Disease, Health Information Management

Submitted: November 14, 2013
Revised: 1st, January 21, 2014; 2nd, April 5, 2014
Accepted: April 10, 2014

Corresponding Author
Ju Han Kim, MD, PhD
Seoul National University Biomedical Informatics (SNUBI), Seoul National University College of Medicine, 103 Daehak-ro, Jongno-gu, Seoul 110-799, Korea. Tel: +82-2-740-8320, Fax: +82-2-747-8928, E-mail: juhan@snu.ac.kr

I. Introduction

The global burden of disease for humans was formerly dominantly acute and transmittable diseases; however, now there is a greater burden of chronic diseases, such as cardiovascular disease, malignancy, and chronic kidney disease (CKD) [1]. This trend is observed in South Korea as in other countries. Despite many efforts to prevent and manage chronic diseases, the cost of disease management is greatly increasing. Chronic disease is affected by multiple factors, such as personal lifestyle, mode of living, circumstances, and socioeconomic status, so the management of chronic disease requires many-sided methods and information sharing regarding those factors [2]. The common causes of CKD, such as hypertension and diabetes mellitus, have a bad effect on the kidneys. When kidney function deteriorates and/or there is proteinuria/hematuria, a diagnosis of CKD is made [3]. When the glomerular filtration rate becomes less than 15 mL/min, renal replacement therapy is needed. This condition is called end-stage renal disease (ESRD). Nearly 1% of CKD cases progress to ESRD. The prevalence of ESRD is over 0.1% of the general population [4]. The prevalence of both CKD and ESRD has been increasing [5]. Despite the features of chronic disease, a multidisciplinary approach has not been taken in the management of ESRD. In other words, information regarding ESRD is not shared among healthcare providers and is not adequately used to improve patient care.

The Health Avatar platform was designed for the management of chronic disease. The platform employs Health Avatar Beans, which includes the health agent and care platform for the management of CKD and ESRD. In the platform, the continuity of care record was maintained with the health agent through the agreement of meanings and structures of data. This article is about the DialysisNet system which is included in Health Avatar Beans for the seamless management of ESRD. For the efficient management of ESRD information, we suggested that the application should be used for the integration and management of data sources of hemodialysis information through the continuity of care record.

II. Case Description

Information about CKD includes data from the beginning of CKD until ESRD. We called the management project of that information Avatar Beans. In this article, we focus on the DialysisNet system, which is used to manage hemodialysis treatment in the renal replacement therapy for the end-stage renal disease. The DialysisNet system was designed through the following processes.

1. Hemodialysis Data Modeling

For the effective management of hemodialysis data, we identified common data elements of hemodialysis infor-

Table 1. Brief headings of common data element of hemodialysis information (individual patient, dialysis, outcome information)

Individual patient data	Dialysis	Outcome
Data collection date	ESRD duration	Death - date
Baseline characteristics	Dialysis	Death - all cause
Name	HD per week	Death - specific cause
Social security number	Dialysis schedule	Hospitalization - cause
Date of birth	Dialysis time	Hospitalization - specific cause
Mailing address	Weight	Medications
Phone number	BP before dialysis	
Insurance status	BP, intradialytic	
Age	BP after dialysis	
Sex	Dialyzer	
Height	Dialysis dose	
Dry weight	Residual renal function	
Nutrition	BUN	
Smoking status	Serum creatinine	
Urine volume	Kt/V	
Mean activity profile	URR	
Blood test before dialysis	AV access1	
Echocardiography	AV access2	
Primary cause of renal failure	BFR	
Coexisting medical condition	DFR	
Functional status	UF	

ESRD: end-stage renal disease, HD: hemodialysis, BP: blood pressure, BUN: blood urea nitrogen, Kt/V: K (clearance of urea), t (dialysis time), and V (volume), URR: urea reduction ratio, AV: arteriovenous, BFR: blood flow rate, DFR: dialysate flow rate, UF: ultrafiltration.

http://dx.doi.org/10.4258/hir.2014.20.2.145

mation (CEDHI) which were obtained from four sources. First, data elements used in ongoing and published original articles were identified (New England Journal of Medicine, Kidney International, ClinicalTrials.gov). Second, data was gathered from the registry sites currently operating (United States Renal Data System [USRDS] [6] and the European Nephrology Quality Improvement Network [NephroQUEST]) [7]. Third, data were obtained from data provided by the Health Insurance Review and Assessment Services (HIRA) [8]. Fourth, the data were classified according to the most frequently asked questions about problems which can occur during hemodialysis. Based on the CDEHI, we classified the groups into individual patients and hemodialysis centers. In addition, the individual groups were separated into general information, hemodialysis information, and outcome information of individual patients. The contents for the hemodialysis centers were separated into general quality information based on the Dialysis Outcomes and Practice Patterns Study (DOPPS) [9] and insurance quality information based on the HIRA content. The CDEHI was separated into content lists (the number of content lists) for individual patient data (183), content lists for hemodialysis center data (137), consultation and transfer forms (42), and reasoning helping data (86). The brief headings of CDEHI are shown in Table 1.

2. Compliance Method with Standard Model

ASTM continuity of care record (CCR) is the standard model for the expression and transfer of health record summaries [10], and ISO/IEC 11179 is the international standard for the transfer of metadata [11]. We used ASTM CCR and ISO/IEC 11179 for the compliance method with a standard model for the CDEHI. According to the contents of the ASTM CCR, we mapped the CDEHI to contents. After mapping, we created the metadata of the CDEHI by the ISO/IEC 11179. This metadata was transformed and parsed into the database while being verified according to the ASTM CCR/XML schema definition (XSD). The CDEHI was matched to the ASTM CCR and transformed to metadata. After removing duplication according to the ISO/IEC 11179 standard, the total number of metadata items in the CDEHI is 551. This metadata was transformed to XML and was proven according to the ASTM CCR/XSD. After that, the metadata was parsed into the metadata registry in the CarePlatform based on the representational state transfer (REST) protocol (Figure 1).

3. Development of DialysisNet

DialysisNet was created as an iPad application with Xcode 5.0.1, iOS SDK 4.0 and Phonegab. The contents of the CDEHI were categorized for effective management. Visualization, the usual interface for CDEHI was also categorized for effective management and convenience (individual patient data tab/hemodialysis information tab/center for hemodialysis/transfer information). The CDEHI graph is shown for the time-period which the user selects. Chest X-ray images were also added to the database. Statistics of all values could be

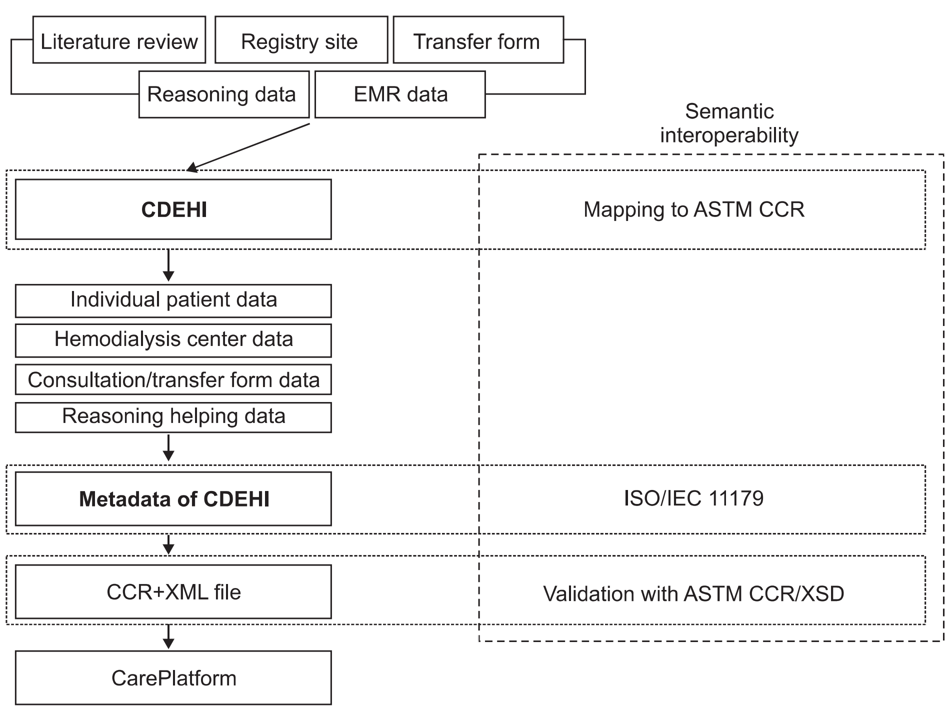

Figure 1. Compliance common data element of hemodialysis with standard model. EMR: Electronic Medical Record, CDEHI: common data elements of hemodialysis information, CCR: continuity of care record, XSD: XML schema definition.

Figure 2. User interface design in DialysisNet. (A) Individual patient data, (B) hemodialysis center data, (C) hemodialysis information data, and (D) transfer form data.

offered by the mean, median, range of value, and percentage. The database comprised section tables around the patient table.

1) Visualization

On the left side of DialysisNet, there is a patient list tab. DialysisNet comprises an individual patient information tab, hemodialysis information tab, hemodialysis center tab, and consultation/transfer form tab (Figure 2). The individual patient information tab can be used to access the general information of a patient, last test results, and last hemodialysis information. The general information of patient includes name, sex, age, address, and causative disease of ESRD. The last test results include complete blood count, blood urea nitrogen, and serum creatinine. The last hemodialysis information includes arteriovenous access information, dialysis time, amounts of urine, blood pressure, and weight change during hemodialysis. The hemodialysis information tab includes general information of hemodialysis, that is, the data of variables during hemodialysis, namely, vital signs, blood flow rate, dialysate flow rate, and dialyzer. The hemodialysis center tab includes a DOPPS estimation tab and an HIRA estimation tab. The consultation/transfer form tab includes the general information of a patient, last tab results, and drug information.

2) Graphics

All test results and variable changes during hemodialysis are shown in graph form. In graphic view, if we select some variables, we can see the changes in variables over periods of 3 months, 6 months, 1 year, and all periods. We can also compare a variable of an individual patient with the mean value of variables of all patients in a hemodialysis center.

3) Images

Though the individual patient information tab, DialysisNet offers access to the last 4 chest posterior-anterior images. When it is touched, an image can be enlarged. DialysisNet offers two-image and four-image formats.

4) Statistics

The hemodialysis center tab in DialysisNet can be used to access statistics about test results and variables. Doctors can see the mean, median, range of variables, and percent change of variables per month. According to the guidelines of DOPPS and HIRA, DialysisNet offers the result of estimation with statistics.

5) Database

In a Star Schema configuration, the tables of the CCR sections are presented separately from the patient table which is at the centered. In the tables of the CCR sections, the attribute of the section is converted into a table. Specific items of hemodialysis information are added to new records in the tables of the CCR sections.

4. Evaluation of Information Transfer

After matching the data, we used CarePlatform for information transfer. Health Avatar is a personalizing healthcare platform for the personal health record, which was developed by the Seoul National University Bioinformatics laboratory. CarePlatform, one of the Clinico-Histopathological Metadata Registries (CHMRs), was developed as a data-access platform with the REST protocol like the Facebook platform. In CarePlatform, the application program interface for specific diseases is employed. The DialysisNet system can be plugged and played using this CarePlatform. The metadata of the CDEHI in DialysisNet is exchanged by the CarePlatform with semantic interoperability. When DialysisNet asked for data from the CarePlatform, the CarePlatform offers the data by query of CCR. By the CarePlatform, the data in patient the CCR can be sent to the DialysisNet (doctor's CCR). By this procedure, data exchange can be achieved with semantic interoperability. When a patient wants to go to another hemodialysis center, DialysisNet is able to generate a transfer form document by using CCD or CCR. A patient could have their own CCD or CCR.

III. Discussion

1. Comparison of CDEHI with Other Means of Data Standardization

Up to now, two registries have been used for hemodialysis information, namely, the USRDS [6] and NephroQUEST [7]. The USRDS was established for the collection, analysis, and sharing of information about patients with ESRD. The information in the USRDS includes baseline characteristics of patients and their transplantation information. However, the information from laboratory results is too limited to be of any value in real practice. With the information on patients' serum albumin, serum creatinine, hemoglobin, HbA1c, and lipid profile, only some of the dialysis information is available, so its usefulness is limited. NephroQUEST was established by the European Nephrology Quality Improvement Network and the European Renal Association–European Dialysis and Transplant Association. With the information on patient's C-reactive protein, calcium, phosphorus, parathyroid hormone, ferritin, lipid profile, hemoglobin, serum iron, and serum transferring, it also has hemodialysis data. The data thus includes all the laboratory results required in the care of hemodialysis patients and provides an outcome indicator of disease with dialysis efficiency. However, the dialysis information is insufficient to expand to check the quality of hemodialysis information. The CDEHI is based on the CCR. Therefore, all kinds of data created in real-practice can be included and can be expanded to check the quality of hemodialysis information.

2. DialysisNet Implementation

DialysisNet is now being implemented in a private hemodialysis center for one month. The total number of patients in that center is 78. For the exchange of data, we installed the CarePlatform on the server. The test results could be sent to the DialysisNet system via this server from the local lab center. DialysisNet will also be operated in a tertiary hospital next month. To check the efficiency and effectiveness of DialysisNet in practice, we plan to compare changes in practice before and after use. To discover such changes, we will use an eight-question survey regarding the frequency of discussion with patients, time-consumed in practice, how cares about that assessment of the hemodialysis center. During this research on the efficiency and effectiveness of DialysisNet, we also plan to use a version of DialysisNet for patients. The patient version of DialysisNet comprising 7 content areas that patient want to know about is now being produced.

3. Comparison with Other Registry on the Evaluation of Hemodialysis Center

Until now, the evaluation of hemodialysis centers has been done using two registries, DOPPS, HIRA. The DOPPS includes nine content categories for the evaluation of hemodialysis centers and a total of twenty countries (not including South Korea) took part in that project. DOPPS associations publish a report on the evaluation results annually. The HIRA contents include six categories for patients and seven categories for dialysis centers. The aim of evaluation for HIRA is for the pay for performance on someday. Both registries are updated annually, so doctors cannot use those results in real-time practice. In particular, when the HIRA requests the data of a patient in a private hemodialysis center, the time and effort to make the report can be a heavy burden for the chief of that center. In this regard, DialysisNet can be an effective solution. DialysisNet can function as a registry for the evaluation of the hemodialysis center, and functions in the real-time. Thus, DialysisNet can enable the creation of real-time registries.

4. Clinical Decision Support System for Practice

Until now, there has been no clinical decision support system in practice for hemodialysis patients. For renal replacement therapy, patients with ESRD must have hemodialysis until the end of life unless they undergo transplantation. Doctors in hemodialysis centers are faced with many repetitive problems. Most of problems fall into the following ten categories: weight, anemia, hyperkalemia, hyperphosphatemia, hypertension, diabetes, transplantation, health checkup, arteriovenous access problem, and edema. DialysisNet offers resources to help doctors make decisions regarding these ten problem areas. If DialysisNet can share transplantation information with the Korean Network for Organ Sharing, more patients could benefit from transplantation.

5. Management of Chronic Disease with Sharing of Health Information

Chronic diseases are multifactorial. Early detection is difficult, and they require long-term treatment [2]. Multifactorial disease cannot be solved by the disease/hospital-centered system. There has been insufficient sharing of healthcare information in such a system, and there has been no participation of the consumer of healthcare–the patient. In this regard, the personal health record concept has merits. DialysisNet, which is based on personal health records, also has advantages that can be instrumental in overcoming the problems of chronic disease in the area of hemodialysis treatment. DialysisNet provides regular health checkup alerts to patients. Through DialysisNet with personal health records, information about chronic diseases can be shared. Also, patient care programs are currently in production, and they are also based on personal health records. Thus, DialysisNet will provide healthcare information to patients, and patient will be able to participate in the healthcare system through their personal health records.

6. Limitations

The hemodialysis information set that was used in this application was not made through the discussion of several healthcare professionals. Also this application should actually be applied to hemodialysis centers before its effectiveness can be thoroughly assessed. Therefore, we plan to have clinical trials including the support of health care professionals.

Conflict of Interest

No potential conflict of interest relevant to this article was reported.

Acknowledgments

This work was supported by a National Research Foundation of Korea (NRF) grant funded by the Korean government (MEST)(2010-0028631) and the Korea Health 21 R&D Project of the Ministry of Health, Welfare, and Family Affairs, Republic of Korea (A112020).

References

1. World Health Organization. The global burden of disease: 2004 update [Internet]. Geneva, Switzerland: World Health Organization; c2014 [cited at 2014 Mar 15]. Available from: http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/.
2. Lee SY. Development of a sustainable health management system for management of chronic disease. Health Welf Policy Forum 2004;(87):72-81.
3. National Kidney Foundation. K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. Am J Kidney Dis 2002;39(2 Suppl 1):S1-266.
4. ESRD Registry Committee, Korean Society of Nephrology. Current renal replacement therapy in Korea: Insan Memorial Dialysis Registry, 2012 [abstract]. In: Proceedings of the Korean Society of Nephrology; 2013 Oct 12; Gwangju, Korea. p. 7-35.
5. Jin DC. Current status of dialysis therapy in Korea. Korean J Intern Med 2011;26(2):123-31.
6. United States Renal Data System. 2012 Researcher's guide to the USRDS database [Internet]. Minneapolis (MN): United States Renal Data System; c2014 [cited at 2014 Mar 15]. Available from: http://www.usrds.org/research2012.aspx.
7. European Nephrologist Quality Improvement Network NephroQUEST [Internet]. Amsterdam, The Netherlands: NephroQUEST; c2007 [cited at 2014 Mar 15]. Available from: http://www.nephro-quest.eu/index.jsp.
8. Health Insurance Reviews and Assessment Services [Internet]. Seoul, Korea: Health Insurance Reviews and Assessment Services; c2014 [cited at 2014 Mar 15]. Available from: http://www.hira.or.kr.

http://dx.doi.org/10.4258/hir.2014.20.2.145

9. Dialysis Outcomes and Practice Patterns Study Program [Internet]. Ann Arbor (MI): Arbor Research Collaborative for Health; c2014 [cited at 2014 Mar 15]. Available from: http://www.dopps.org/.
10. American Society for Testing and Materials. ASTM E2369-12 Standard Specification for Continuity of Care Record (CCR) [Internet]. West Conshohocken (PA): ASTM International; c2014 [cited at 2014 Mar 15]. Available from: http://www.astm.org/Standards/E2369.htm.
11. Metadata Standards. ISO/IEC JTC1 SC32 WG2 Development/Maintenance: ISO/IEC 11179 [Internet]. Centennial (CO): Center for Biomedical Informatics and Information Technology, National Cancer Institute; c2013 [cited at 2014 Mar 15]. Available from: http://metadata-stds.org/.