

Development of Common Data Elements to Provide Tele self-Care Management

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ABSTRACT

Background: Self-care management could empower patients to management of their health. Tele-health is the remote exchange of data between a patient and medical staff to improve healthcare quality. **The aim** of this research was developing common data elements to provide Tele self-care management and improve quality of care. **Materials and methods:** this was a cross-sectional study based on Delphi approach was done in 2011. Data was extracted by three sessions' of conversation with 20 faculty members. Data had more than 75% agreement was inserted in

minimum data element list, data with lower than 50% agreement was considered as failed data and whom was agreed between 50%-75% of participants were reconsidered for conversation until three sessions and after re-voting it was failed or accepted. **Results:** Results showed that self-care divides in three main categories and also some sub-categories including: 1-Immunity and Safety with two subcategories (A: Prevention of Disease and B: Awareness and Knowledge about Disease); 2-Health Security and Maintains in six subcategories (A: Laboratory Test Results; B: Vital Data Monitoring; C: Rehabilitation; D: Drug Information; E: Follow up and F:

Dental Health), 3- Well-Being Education in four subcategories (A: Nutrition; B: Health Promotion; C: Life Style Improvement and D: Patient Activity). **Discussion:** Consideration of all aspects of self management including information about prevention of disease, knowledge about disease, laboratory test result, vital signs monitoring, rehabilitation, drug information, follow up, dental health, nutrition, health promotion, life style improvement and patient activities is necessary. **Key words:** Common Data Elements, Hospital Information System, Self-Care, Self-Management, Tele health.

1. INTRODUCTION

Self-care management could empower and prepare patients to management of their health. Healthcare with emphasizing on patients' central role for taking responsibility of their own health is important (1) and self-management programs aimed to give patients such knowledge and skills to manage their complains in their own living environments constantly (2, 3, 4). Self-care management encompasses a variety of actions and skills are important for both treatment of an illness and also prevention of its complications (5). Examples of self-care themes include recognition of disease symptoms, medication use, management of physical and emotional stresses, self-monitoring activities, exercise, diet, smoking cessation and others (6). In spite of undeniable evidence on the importance self-care management, usually it is neglected by both

patients and policy makers (7, 8). Institute of Medicine (IOM) has produced several important documents that have substantial influence on health care; in one of these documents, titled *Crossing the Quality Chasm: A New Health System for the 21st Century*, focuses on substantial effect of administrators, health professionals, and especially patients in process of health care. The report lays out ten rules that these players should act on. Firstly patients should receive care whenever they need not only during face-to-face visits. This rule implies that except face to face visits, the health care system should be responsive at all times (24 hours a day, every day) and access to care should be provided over any other possible ways like internet and telephone (9). Researchers found that use of information systems promises significant advances in patient care (10). Health Information Tech-

nology (HIT) has been increasingly used and studies on its role in data transfer and health care delivery for patients have grown continuously. The Robert Woods Johnson Foundation described HIT as "the use of a variety of electronic methods for managing information about the health and medical care of individuals and groups of patients (11). Tele-health is defined as the remote exchange of data between a patient at home or other place and medical staff to assist him in diagnosis and monitoring of disease (12). It has been suggested as a way to improve healthcare quality, including better management of the processes of care and protection of patient safety (13, 14). Consequently it is believed that effective use of Tele-health could cause significant cost saving (15). A review of the evidence showed that HIT can improve the quality and delivery of care (16).

Some interventional researches suggested that use of information systems is favorable (14) and it appears to be a beneficial adjunct to patients' education for self-care management (17, 18, 19, 20). To assist patients in acquiring the knowledge of self-care some education programs have been developed helping information systems (21, 22, 23). Registration of data in such systems must be done manually and this process is time-consuming that it will prevent to adopt such systems for patients' education. To prevent human errors and save time, these systems are improved by integrating the hospital information system to take digital data system required, such as medication and lab test (24). Although these technologies are improving continuously as new technologies are developing every day, the common feature is that they all allow remote access to a service (e.g. practitioner, nurse and specialist) and provide a means of supporting the provision of healthcare self management (25, 26).

Minimum data sets have been proposed as a method of supporting clinical, managerial, research and educational applications through the amassed data that are recorded (27) and as a basis of providing a means for supporting self management. It is identified as an appropriate set of data elements (14). Three stages in the successful development of a set of data elements have been identified (28). a) Selection of data terms; b) Turning data into information. c) Applications. There are only few studies have focused on the development of Minimum Data Elements for hospital information systems related to self-care management. Then this study was done to build a Minimum Data Elements for providing Tele self-care management to assist patients with a suitable, instant and individualized health education documents.

2. METHODS

A cross-sectional study by using Delphi approach was done in 2011. An elementary list of minimum data compiled based on reference books and articles (29-31), then a questionnaire developed. The questionnaire

had face and content reliability as authenticated by health information management experts. Data of Delphi technique extracted by three conversation sessions with 20 faculty members of nursing and health care information management disciplines. In each session, discussion and exchange of view about minimum data was done and the elementary list revised based on experts recommendations and frequency and percentage of agreed and disagreed for each data computed and agreed data with 75 percent to up inserted in Minimum Data Elements List for hospital information system, agreed data with 50 percent and down failed and for those data agreed between 50%-75% until three sessions conversations and discussions continued and failed or accepted after that.

3. RESULTS

After three sessions conversation and exchange of viewpoints of experts, Self-care topics divided in three fields and some sections, including:

- * Immunity and Safety in two sections (A: Prevention of Disease and B: Awareness and Knowledge about Disease);

- * Health Security and Maintains in six sections (A: Laboratory Test Results; B: Vital Data Monitoring; C: Rehabilitation; D: Drug Information; E: Follow up and F: Dental Health);

- * Well-Being Education in four section (A: Nutrition; B: Health Promotion; C: Life Style Improvement and D: Patient Activity).

The most frequency elements in each field and related sections were following:

- * In immunity and safety fields, A: preventive of disease; need to special vaccination. B: Awareness and knowledge of disease: length of disease duration, complications, offer good information resources and diagnostic and treatment cost resource.

- * In security and maintain fields: A: laboratory test result: hemoglobin, hematocrit, blood group, blood urine nitrogen, blood sugar, B: vital data monitoring, blood pressure and temperature. C: Rehabilitation: Heart rehabilitation-Patient-centered test, Secondary prevention, Educational

consultation programs, Nutritional consult, ECG controlling, Heart timetable checkup.

- * Training use of pacemaker: Periodical visit for pacemaker function, Note about minor repair on pacemaker, Keep away assault, Avoiding airway travel, Had Identification card;

- * Optical problems Optical instrument, Job consultation, Special educational optical techniques;

- * Movement and functional rehabilitation, Range movement evaluation, Reflexes movement evaluation, Sensation and movement test, Recommendation notes, Use of other prosthesis;

- * Convenient exercise: Educational pamphlet. D: Drug information: Drug consumption dosage, Drug consumption duration, Drug consumption time, Drug form, Recommendation during consumption, Drug way consumption, Drug preparation methods, E: follow up: Need to encounter, Date of encounter, Number of encounter, Daily routine check up for ulcer in diabetic patient (place and condition for encounter not accepted and failed). Dental Health: Teeth-brushing methods, Use of Tooth string methods, Mouth washing liquid, Chewing brittle food.

Most frequency for essential minimum data elements for well-being education field was Nutrition-essential consumed materials - hypersensitivity against drug. hypersensitivity against planet not accepted in this fields. B: Health Promotion, Use of instrument methods, Education about disease epidemic not confirmed. Life style improvement, Rest: D: Activities, Motion and exercise. In this section, bathing recommendation not accepted and failed.

4. DISCUSSION

The tele-health may offer a way to provide care and encourage self-management for patients. Involving the patient in the care process using information technology is an active area of research (32, 33). The Internet websites with health information are abundant (35, 36, 37). Projects where patients access their electronic medical record (38), send e-mails to their

physicians (39, 40, 41), or send data to be monitored have also been described, but what are the common data elements for good self management through hospital information systems? In this paper we developed common data elements to provide tele self-care management. Based on research results the common data elements recommended in three fields and some related sections. The first of all was Immunity and Safety data with two sections, Prevention of Disease and Awareness and Knowledge about Disease. Other researcher showed that tele health technologies have been used with good results in areas of preventive care and management of certain disease especially in chronic diseases including osteoarthritis, heart disease and diabetes (42) and also used for consult with patient for health behaviors and give information about disease (43) and patient had satisfaction with these systems (91%) (44) and also have emphasized on improve knowledge with give information about nature, causes, stages, signs and symptoms of disease for self management and better recovery from it (45, 46). These researches have contingency with this results study. However some other fields were recommended by other studies. In a research self management organized in four fields including, present information for improvement of life style, taking care of short time illness, taking care of chronic disease and taking care after hospital discharge (47) or recommended to show information about care of body signs, treatment of disease attacks (45) give information about progress of care and risk factors (48, 49) also emphasized these information did not consideration in this research and is not contingency with the results. As this research studied about common information but in consistency research, self care survived in healthy people (47) or in special disease then the results were explainable. The same research on specific disease, especially diabetes, leukemia, hemodialysis, arthritis and so on for provide specific information proposed.

In second field: Common data for Health Security and Maintains fields

with six sections offered including common data for A: Laboratory Test Results; B: Vital Data Monitoring; C: Rehabilitation; D: Drug Information; E: Follow up and F: Dental Health. Other researchers showed that patient to be inclined to access to rest results (50, 51, 52), monitor chronic disease including asthma, hypertension, congestive heart failure and high risk pregnancy (43) chemotherapy side effects and symptoms of patient receiving chemotherapy (43, 53) and had satisfied with using these systems (94%) (44). The patient had concern about and problem with when they used medical equipment and need to get information about application and some other information about these equipment (54). In respect of drug information, studies show that this information had most frequency. One of them reported that the most frequency of data exchange was about medication and of the 350 medication-related exchanges, 196 (56%) were categorized as routine medication discussion, such as ordering and/or refilling medications. Alternative therapy OTC medication 23 (6.6%), side effects 21 (6%) and some of them were question due to forgetting a dose, the medication regimen, increasing or decreasing the dose or stopping the medication, use of herbs or using other non-prescribed medication (55). As view point of patient information was very important and was the first priority between all of the medical information (49).

These researches have contingency with this study. However other surveys revealed that information such as methods of operating of equipment (55%) (57%) or methods of operating of equipment (55). That was not consistence with these results.

In third field, Well-Being Education in four sections accepted, A: Nutrition; B: Health Promotion; C: Life Style Improvement and D: Patient Activity. Majority of surveys reported that had information about mobility were very important for self management (46, 47, 56, 57, 58, 59, 60) and education could improved life style (61, 62, 63, 64) and proposed that the manner of mobility, programming

for exercise, jogging and rest educated to patient. These finding was the same as us results, but on the other hand related to other people suffering the same disease resulted to better self management (65, 66). That is not as the same as us results. Regarding to this matter that the disease can change working (75%), social living (72.5%), family life (83%) (56).

And according to the evaluations the contents generated by this system were acceptable for clinical patient education and helpful to nurse's work (24) and suggested that personal health record designed and establish for better patient access to medical information and use of data base (67, 68) hospitals should moved to apply self management and it seems that hospital information systems apply a good opportunity for self management. It was recommended that with the designed execute and repeated evaluation can improve self care managing with hospital information links. The present study offers the common for self care management through health information systems and the results show that consider all aspects of self management including information about prevention of disease, awareness and knowledge about disease laboratory test result, vital data monitoring, rehabilitation, drug information, follow up, dental health, nutrition, health promotion, life style improvement, patient activities are necessary. This study was not attention specific data for special groups of patients, disease or hospitals that recommended considering in future research.

To make available any information for patient use it should be attention that this information must be simple and based on patient conception (69) also with consideration of increasing of chronic provide the essential information is inevitable to improve personal health and decrease their need to advanced and expense care. As attended education to patient need to time, staff, adequate information and good environment (56) and as is recommended that the health care authorities use self care educational methods and short

follow up .It seems that provide information through hospital information system with use of these common data developed is suitable.

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