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An ontology-based approach to patient follow-up assessment for continuous and personalized chronic disease management

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ABSTRACT

Objective: Chronic diseases are complex and persistent clinical conditions that require close collaboration among patients and health care providers in the implementation of long-term and integrated care programs. However, current solutions focus partially on intensive interventions at hospitals rather than on continuous and personalized chronic disease management. This study aims to fill this gap by providing computerized clinical decision support during follow-up assessments of chronically ill patients at home.
Methods: We proposed an ontology-based framework to integrate patient data, medical domain knowledge, and patient assessment criteria for chronic disease patient follow-up assessments. A clinical decision support system was developed to implement this framework for automatic selection and adaptation of standard assessment protocols to suit patient personal conditions. We evaluated our method in the case study of type 2 diabetic patient follow-up assessments.
Results: The proposed framework was instantiated using real data from 115,477 follow-up assessment records of 36,162 type 2 diabetic patients. Standard evaluation criteria were automatically selected and adapted to the particularities of each patient. Assessment results were generated as a general typing of patient overall condition and detailed scoring for each criterion, providing important indicators to the case manager about possible inappropriate judgments, in addition to raising patient awareness of their disease control outcomes. Using historical data as the gold standard, our system achieved a rate of accuracy of 99.93% and completeness of 95.00%.
Conclusions: This study contributes to improving the accessibility, efficiency and quality of current patient follow-up services. It also provides a generic approach to knowledge sharing and reuse for patient-centered chronic disease management.

1. Introduction

1.1. Challenges of current chronic disease management programs

Chronic diseases have become the predominant challenge to global health as a result of demographic ageing, the globalization of unhealthy lifestyles, and uneven distribution of health-care resources [1]. Despite national and international efforts to address this challenge, the current situation is not encouraging. According to the 2014 global status report on prevention and control of chronic diseases released by the World Health Organization (WHO), 38 million people die from chronic diseases each year, and this number is projected to increase by 15% globally between 2010 and 2020 [2]. The adverse effects of chronic diseases pose an ever increasing threat to individual and community health, economic growth and social development. Finding effective strategies to prevent and manage chronic disease is essential.

The prevention and management of chronically ill patients require multiple coordinated and mutually-reinforcing actions over long periods of time to address the complex interactions across risk factors, diseases, patient conditions and treatment modalities. These actions include epidemiology and surveillance to monitor trends and track progress, policy and environmental approaches to promote health, clinical interventions to improve the delivery and use of health-care services, and links between community programs and clinical services to improve and sustain the management of chronic conditions [3]. However, current chronic disease management programs are often discrete and

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targeted, usually with a focus on highly specialized diagnostic and therapeutic interventions at hospitals, which is not sufficient to cover the lifetime care process of patients suffering from chronic disease. Integrated care programs are required to improve the continuity, efficiency, and quality of chronic care services [4].

1.2. The role of clinical follow-ups in the chronic care model

The key principle of integrated care programs is to shift healthcare practices fundamentally from short-term, fragmented and reactive care to long-term, consistent, and proactive care that is organized, structured, and patient-centered through a combination of multidisciplinary team care and planned interactions with patients. This principle can be illustrated by the chronic care model (CCM) developed by Wagner et al. [5], which emphasizes productive interactions between patients and health-care providers through community resources and policies, self-management support, delivery system design, decision support, and clinical information systems. A recent review showed that successful strategies in chronic disease care are consistent with the concept of the CCM; however, full implementation of this model is still not the norm [6].

Considering the complex and variable interactions between risk factors, patient conditions, and irreversible disease progression, there is general agreement that the ultimate goal of chronic disease management is not to cure but to control the disease as well as independent living [7]. As patients are the day-to-day managers of their chronic conditions throughout the care process, patient self-management should be placed at the center of the CCM [8]. While health education programs are already available to enrich patient knowledge about appropriate treatments, lifestyles, and use of health-care resources, they provide little information on patients' personal achievement and disease progression, which is indispensable for patient-centered disease control and health promotion [9,10].

Clinical follow-up is another important part of self-management that provides such information. During these visits, patient's vital signs, symptoms, lifestyles, medication, and other relevant conditions are reviewed based on the key indicators of disease outcome that are collected, analyzed and evaluated, and instructions on adhering to or modifying current management strategies are given by responsible case managers to enhance patient awareness of and skills in self-management, improve their conformance to treatments, and decrease unnecessary health care utilization [11–14]. However, traditional follow-up protocols published by local, national, or international health-care authorities are based on a set of static assessment criteria that are neither comprehensive nor detailed enough to handle the particularity and complexity of chronically ill patients. In addition, lack of computerized tools also leads to extensive manual work, which leads to inaccuracy and inefficiency of the decision-making process.

1.3. The objectives of this study

Our previous studies have contributed to addressing some aspects of the CCM, such as personalized care planning [15–18], meaningful use of electrical medical records (EMR) [19–22] and clinical decision support (CDS) [23,24]. This study aims to extend previous efforts toward full implementation of the CCM by developing a knowledge-based system for patient follow-up assessments. We proposed an ontology-based framework for systematically capturing, synthesizing, modeling, sharing, and operationalizing the information required for the follow-up management of type 2 diabetic patients. Major components include a patient data model, a medical domain knowledge model, and a set of patient assessment models. A clinical decision support system (CDSS) was developed based on a service-oriented architecture (SOA) [25] to implement this framework for automatic selection and adaptation of standard assessment protocols to suit patient personal conditions. We evaluated our method in terms of technical validity and functional usability using real patient data.

2. Related work

2.1. Ontology-based knowledge representation in health care

Ontology, originally defined as "a formal, explicit specification of a shared conceptualization" [26], is a widely adopted methodology in computer science for knowledge representation. By explicitly defining the commonly approved conceptual model of a particular domain using formal modeling structures – classes representing concepts, properties describing attributes of and relationships between the concepts, restrictions specifying logical constraints on concepts – ontology facilitates knowledge sharing and reuse in an intuitive and machine-understandable way [27]. Instantiated domain ontology is also known as a knowledge base, which together with various problem-solving methods constitutes the foundation of many intelligent applications and systems in knowledge-intensive domains.

A variety of biomedical ontologies have been developed [28–30]. These ontologies can be classified into three categories according to the type of knowledge being modeled: (1) ontologies for representing controlled vocabularies, which serve the general purpose of data integration and interoperability among disparate information systems, such as the ontology-based representation of standard biomedical terminologies on BioPortal [31]; (2) ontologies for representing declarative knowledge, which are typically used to describe the static concepts and relationships within a healthcare organization or a medical research domain, such as the Actor Profile Ontology for defining roles and responsibilities in the healthcare service network, and the Case Profile Ontology for representing the knowledge graph of chronic diseases in the K4CARE project [32]; and (3) ontologies for representing procedural knowledge, which specify the conditions, decisions and actions that constitute the hierarchical task network model of a dynamic clinical workflow, such as those guideline representation ontologies for evidence-based clinical decision support, representative ones include Asbru, EON, GLIF, and SAGE, developed in the United States; and GASTON, GUIDE, PRODIGY, and PROforma, developed in Europe [33–35].

However, work in this area has not yet reached a standard due to the heterogeneity in the structure and semantics of the knowledge being modeled. In addition, most of these ontologies involve complex modeling primitives, making it difficult for knowledge engineers as well as healthcare staff with no advanced programming skills to understand and manipulate. Hatsek et al. proposed a method to address the above mentioned problem by designing a scalable architecture for integrating the procedural and declarative knowledge in clinical guidelines [36]. A central repository for hybrid guidelines was developed, and a graphical framework was developed for collaborative specification and maintenance of guideline-based knowledge by expert physicians and knowledge engineers. In this study, we demonstrated how these ontologies and frameworks can be reused and integrated. Methods for representing explicit as well as implicit medical knowledge were proposed to provide comprehensive support for the decision-making process during clinical follow-ups.

2.2. Standards for patient data interoperability

Multiple sources of patient data need to be collected and analyzed to provide continuous and personalized chronic disease