

Telemedicine and Diabetes Management: Current Challenges and Future Research Directions

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Abstract

Telemedicine is lying between fading and future. Several clinical studies and critical reviews have been published recently, but the results are inconclusive and the adoption of telemedicine interventions in clinical practice is slow. This article discusses some of the current problems related to the adoption of telemedicine systems and focuses on the information technology solutions that appear to be most promising for diabetes management in the near future. Context awareness, user modeling, intelligent dialogues, and integrated information systems are presented. Some potential future scenarios for the adoption of telemedicine, which combine novel technologies and new organizational models, are also discussed. Within those scenarios, telemedicine may prove to be a good instrument to support health care providers in the effective management and prevention of diabetes mellitus.

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Introduction

Since the late 1970s a strong interest has been devoted to the design and implementation of information and communication technology (ICT) systems aimed at supporting the management of diabetes mellitus (DM), mainly in the areas of electronic patient records, decision support systems, and telemedicine.¹⁻³ In particular, diabetes care is probably one of the fields where telemedicine, e-Health, and consumer-health solutions have been more widely tested.⁴⁻⁶ The chronic nature of the disease and the need to empower patients make DM a “natural” context to test ICT as a means

to support home care. Some of the proposed systems are now running large clinical trials, although a few of them have become part of disease management programs, able to support multifaceted interventions for patient care.^{5,7} Several recently published reviews, meta-analyses, and commentaries have summarized the main outcomes obtained in an effort to understand the current problems related to a widespread implementation of such technologies.⁸⁻¹⁴ By synthesizing the results obtained, some evidence seems to be now available. (1) There are a number of available technological solutions

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Abbreviations: (DARTS) Diabetes Audit and Research in Tayside, (DIP) diabetes information profile, (DM) diabetes mellitus, (EPR) electronic patient records, (GPs) general practitioners, (HCO) health care organization, (ICT) information and communication technology, (IDEATel) Informatics for Diabetes Education and Telemedicine, (M2DM) Multi-Access Services for Managing Diabetes Mellitus, (SfMS) Serviceflow Management Systems, (VHCO) Virtual Health-Care Organization, (VoiceXML) Voice eXtensible Markup Language

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that allow for easy implementation of a telemedicine program; such implementation can be performed through different ICT settings, including modems, mobile phones, and the Internet. (2) Type 1 diabetic patients management through telemedicine leads to a reduction in hemoglobin A1c, is received well by patients, and allows for better patient empowerment. However, the magnitude of the clinical effects is rather limited; moreover, because many studies had different criteria for selecting patients and controls and different approaches for the treatment of control groups, an unbiased data analysis is extremely difficult. (3) A key to the success of a telemedicine program is to address both clinical and organizational issues clearly, comprising the a priori evaluation of the telematic treatment needs, of the goals and duration of the telemedicine program; it is also crucial to define precisely the patient enrollment criteria and the telemedicine treatment protocol, including the roles and responsibilities of caregivers. (4) There is still a substantial lack of economic studies related to the implementation of telemedicine programs, and a clear payment model has not yet been defined. (5) There are still concerns regarding privacy and security issues of these systems.^{15,16}

The reasons why telemedicine is so difficult to evaluate have been brilliantly reported by Friedman and Wyatt¹⁷: those reasons are common to many ICT systems in health care. First of all, while telemedicine intervention is the implementation of a technology-enabled disease management program, it is not a drug intervention, as it has an impact at the same time on the patients and on the caregivers. In the DM management context, it can be considered an “organizational” intervention. As a consequence of that and the nature of the disease, it is unlikely that the outcomes of such intervention will have a large magnitude in a short time. The Sperl-Hillen study,⁷ which reports the improvement of a new disease management program, needed more than 5 years to clearly show clinical advantages. Being an organizational intervention, it is extremely difficult to carry on a randomized clinical trial to evaluate the clinical outcomes without some bias, such as the lack of patient stratification with respect to socioeconomic factors or the lack of randomization of the health care personnel. Telemedicine is therefore the perfect candidate for suffering from the following “evaluation paradox” (see Friedman and Wyatt¹⁷ for a detailed discussion): a health care organization (HCO) would be keen to adopt a telemedicine system if it has shown to be clinically valuable, but HCOs would need to adopt it in order to show such a value. Because telemedicine is related to

organizational changes, it can reach its maximum benefit only if it is part of a routine work practice, which will be unlikely without clinical evidence. To complicate the situation further, the “notoriously rapid evolution of computer hardware and software means that the time course of an evaluation study” may be greater than the lifetime of the ICT solutions used in the telemedicine program (see, for example, the Diabetes Control and Complications Trial^{17,18}).

It is finally important to mention that telemedicine studies often do not report any technical or usability evaluation; however, a telemedicine solution is usually made of a set of software tools with different user interfaces, speed performances, and communication standards. Often, those “details” are crucial in determining the acceptability of patients and physicians.

As a technologist, the author believes that, looking at the current technological solutions, several important research questions must be pursued to improve the quality of the services currently provided; those improvements can be crucial to an exit from the evaluation paradox. This article describes some of those improvements.

Research Directions for ICT in Diabetes Management

A number of unparalleled opportunities are now available to implement disease management and prevention programs based on the current advances of ICT research. In particular, the areas of user-centered design, mobile communication, context awareness, and wearable systems seem very promising for the next telemedicine systems implementation. Those advances enable the design of new telemedicine systems devoted to support all the actors involved in DM management and prevention: patients, diabetologists, general practitioners (GPs), case managers, and health care policy makers.

Supporting Patients through “User Modeling” and “Context Awareness”

Traditionally, computerized systems have been classified as visit-by-visit systems and day-by-day systems, with the first being aimed at supporting physicians and the second helping DM patients in their self-management activities.¹⁹ The availability of telemedicine solutions has changed this kind of paradigm, potentially providing patients and physicians with the same kind of information about self-monitoring, although with different roles and responsibilities.

The majority of the past efforts have been devoted to the design of systems for insulin management. However, the current research frontier is related to citizen and patient empowerment through user modeling and context awareness.

In the area of user modeling, different ICT solutions have been proposed over the last two decades, with particular reference to lifestyle behavior change. These systems provide health behavior change information to citizens based on a variety of behavior theories^{20,21} using different communication media, ranging from Web sites to computer telephone interfaces (CTI). From a clinical viewpoint, they have been applied to a wide number of behaviors, including physical activity promotion, diet adherence, and medication regimen adherence. Overall, these systems have been shown to be effective in a number of randomized clinical trials.²²

Among those kinds of systems, automated dialog systems based on natural language processing and generation seem very promising for DM management, particularly DM type 2.²³ An intelligent automated dialogue system is usually based on the following components: a natural language processing and understanding module able to process the patient speech on the basis of specialized grammars; a knowledge base and a patient model able to generate the proper answers; and finally, a natural language generation module able to provide natural language feedbacks to the patients. The patient model and the knowledge base allow one to customize the dialogue and to implement the so-called "mixed-initiative" strategies in which the computer system is able to change the dialogue prompts based on the quantity and quality of information provided by the patient. Such kinds of system have been tested in the area of hypertension management within projects²⁴⁻²⁶ funded by the European Commission. More recently, the ADARTE (Adaptable Dialogue Architecture and Runtime Engine) project has also extended the Homey results to DM management,²⁷ relying on the most recent technologies, such as the Voice eXtensible Markup Language (VoiceXML).²⁸ The main objective of VoiceXML is to use the technologies developed for Web-based applications to create advanced computer-based audio dialogues.

Another interesting research area is the improvement of the quality of Internet-based services. Ma and colleagues²⁹ have described a new system for the delivery of information and communication support to DM patient on the Internet. The system is able to select patient-specific information, prioritize diabetes

learning topics, and define individualized agendas for patient-physician encounters on the basis of the so-called "diabetes information profile" (DIP). The DIP is a model, i.e., a multifaceted profile, of the user that is progressively updated on the basis of clinical data and of patient interaction with the system. The technology has been evaluated through a small clinical study, which showed its potential effectiveness in providing useful information to patients.

Promising future directions also involve wearable computers, personal digital assistants, and mobile phones as platforms for health behavior change interventions.³⁰ Wearable computers are computers worn on the body.³¹ Usually, wearable computers allow a constant interaction between the computer and the patient and enable multiparameter monitoring, including vital signs, biological signals, and movements. Wearable computers are therefore particularly suitable for getting information about the current health status and lifestyle of a patient.³² Examples of wearable devices are intelligent biomedical clothes, which incorporate electronics into functional clothes. Intelligent clothes, together with user feedback devices, may form a complete system. This has been tested in different research projects. One of those is the MyHeart project, funded by the European Commission.³³ The main innovations in this project are the "combination of novel wearable technologies (novel textile and electronic sensors, personalized algorithms, on-body computing) and user feedback and motivation concepts, in order to make a breakthrough towards new applications for prevention and early diagnose possible."³³

Wearable computers are able to provide "context-aware" health care services. Context means the interrelated conditions in which something exists or occurs, including what is known about the participants in the communication relationship. Therefore, context will regard not only all the user data and information collected, but also something related to the "presence concept."³⁴ In telecommunication networks, the "presence information" is an indicator of user willingness to communicate. Within context-aware computing, presence means that the user is willing to provide a large quantity of information, which will enable the receiver to better interpret what is happening. This idea is very intriguing for patient monitoring, although there are very few examples of running clinical applications.³³

Context awareness can also be achieved through other less sophisticated technological solutions, which would be of interest in order to seamlessly integrate support

into the users' everyday lives and to initiate interaction with the user, such as short message service.³⁵ The availability of such technologies can help better define the "context" in which the conversation between the user and the helper application occurs.

The knowledge about the user (user modeling) and the context (context awareness) in which the monitoring activity is carried out open an interesting area of research, which will also concern the customization and delocalization of decision support interventions. As regarding diabetes care, mobile technology telemedicine solutions are under implementation and testing. It is likely that, in the near future, such telemedicine systems will exploit the ideas coming from user modeling and context aware computing. This will allow one to fully utilize the potentials of mobile devices.

Supporting Organizational Changes by Distributed Electronic Medical Records

Many of the computerized systems described in the literature have been designed primarily to manage DM type 1 patients, in accordance with the "specialist-patient" model of health care^{36,37}; however, current interests are directed toward the management of DM type 2 within a "specialist-GP-patient" model. The current trend is to integrate guidelines and decision support systems as reminders within electronic patient records (EPR) to support complex primary care interventions. The need of integrated solutions is also advocated by the substantial lack of clinical evidence that stand-alone, guideline-augmented EPR may be effective in clinical practice.³⁸ An interesting example of an integrated system is the Diabetes Audit and Research in Tayside (DARTS), which is a validated population-based diabetes information system that collects data from different sources, including hospital admissions, diabetes clinic visits, and diabetes medication. DARTS has been redesigned to overcome the problem of "inertia to change," which is considered the main reason for the sporadic uptake and partial use of ICT-based systems. DARTS combines different technologies to allow for universal data collection, guideline provision and implementation, and others. Currently, DARTS is used in 1000 general practice clinic sites and in 50 major hospital clinics, routinely managing a diabetic patient population of more than 160,000 patients.³⁹ Another relevant integrated ICT intervention is the Informatics for Diabetes Education and Telemedicine (IDEATel) project, funded since the year 2000. IDEATel is designed to provide a telemedicine service in both urban and rural economically disadvantaged areas within New York State. The project involved 1500 diabetes patients, with half of them being managed through a

telemedicine intervention. Patients, GPs, case managers, and specialists are connected by means of an Internet service; the telemedicine service is fully integrated with a health care information system and is empowered by guideline-based reminders and alerts. After the first year of implementation, some improvements in the clinical outcomes had been observed, particularly in blood pressure and low-density lipoprotein; interesting results have also been reported on the psychosocial outcomes of the telemedicine intervention.^{13,14}

Finally, an interesting research effort has been represented by the European Multi-Access Services for Managing Diabetes Mellitus (M²DM) project. The main goal of this project was to develop and test a multiaccess service for managing all types of diabetic patients. The basic concept is to collect data in a central database server that can be accessed through the Web, through the phone, or through dedicated software for data downloading from a glucometer. The M²DM system is composed of Web access, a computer telephony integration service based on an interactive voice response system, and a smart modem located at home. The Web pages are optimized for different access modalities, including mobile devices. A distinguishing feature of M²DM is exploiting technology for managing the knowledge available to patients and physicians. To this end, the information flow is regulated by a scheduler called Organizer that, on the basis of the knowledge on the health care organization, is able to automatically send emails and alerts, as well as to commit activities such as data analysis to software agents. Many decision support tools are integrated in the system, including case- and rule-based reasoning, as well as modeling and simulation software. Four medical centers and more than 60 patients have been involved in a 1-year randomized controlled evaluation, which showed promising clinical and evaluation results, although not statistically significant in all medical centers.^{6,35}

A step forward toward health care-distributed information systems is represented by Serviceflow Management Systems (SfMS), which are aimed at supporting communication between different information systems on the basis of work flow concepts. The basic idea of SfMS is to provide a technical and conceptual infrastructure for handling the information and communication needs of chronic diseases management. To this end, the different health care organizations involved in disease management should be seen by patients as only one organization (Virtual Health-Care Organization, VHCO), which provides both virtual and face-to-face encounters. A SfMS implementation in the area of diabetes management has been proposed by Panzarasa and colleagues⁴⁰; such

a system embeds EPR and telemedicine functionalities as end-user applications, as well as a module for interorganizational communication based on contracts and on XML messages. This implementation was refined further by Leonardi and colleagues,⁴¹ who formalized the model of the care process using a work flow management system called YAWL (Yet Another Workflow Language) and an organizational ontology representing the VHCO; a language for communication was also defined, based on software contracts represented as XML documents. This kind of technology is, however, still at the stage of experimental testing; if adopted, it could provide benefits not only to diabetes care, but also to the management of all chronic diseases.

Discussion

As described in this review, although telemedicine still lies in the debate between “fading” and “future,” ICT will provide us with new powerful instruments for the implementation of novel DM management programs enabled by technology.

As regards telemedicine, looking at the current state of evidence, an important result has already been achieved: a properly implemented telemedicine system is safe and sound for managing DM patients. The evaluation of its cost-effectiveness may, therefore, be related to the real needs and motivations of the different HCOs.

In the author's view, the future will lead to two kinds of telemedicine interventions: those that are long term and those that are short term. Long-term interventions will be part of the redesign of chronic disease management, which will be based on frequent communications among GPs, specialists, and patients. In this case, the concept of telemedicine will be subsumed by the idea of a distributed health care information system. The first examples of those kinds of complex IT infrastructures are given in Italy by the Social and Healthcare Information systems of the Lombardia and Veneto regions, which are trying to connect GPs, hospitals, and pharmacies in a single, distributed, regional health care delivery network.⁴² Because the cost of telemedicine technology is negligible with respect to the overall cost of such IT systems, the challenge in this case will be the organization of information flows and clinical decision making. Potentially, the exchange of low-frequency information between the actors will be probably sustainable with current health care personnel by optimizing the periodic visits of chronic patients, but a careful cost-effectiveness analysis will have to be performed. Short-term interventions will, however,

be designed for particular classes of patients, such as pregnant women, newly diagnosed type 1 DM patients, patients with brittle diabetes, patients suffering from complex clinical conditions, patients who are starting to use the closed-loop control system, and individuals who need life-style monitoring. In those cases it will be possible to design evaluation studies, which will have to show IT soundness, usability, and clinical effectiveness. Both long- and short-term interventions will gain advantages by the continuous progress of technology, with particular reference to the ones described in this article.

Conclusions

Although the adoption of telemedicine in clinical practice is still low and the clinical outcomes of telemedicine interventions are only partially satisfactory, there are several reasons for fostering research in this area. First of all, DM management worldwide is far from having reached the desired therapeutic targets. On the contrary, the increase of DM prevalence, population aging, and health care costs are going to worsen the current situation.⁴³ The widespread adoption of ICT in everyday life, including, in particular, the Internet and mobile phones, is providing a great opportunity to improve the organization of DM care delivery by improving and optimizing communication among patients, health care providers, and health care systems. Of course, it is important to note that while telemedicine can support changes and foster communication and better treatments, it does not cure people by itself. Future research in ICT for DM should therefore concentrate on providing new sophisticated technological tools and instruments to increase the quality of telemedicine solutions, while at the same time designing telecommunication models able to support the health care delivery process more effectively.

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