Renal Telemedicine and Telehealth – Where Do We Stand?

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Abstract— **Chronic renal patients and patients with end stage renal disease are a distinctive patient group with a serious, chronic and irreversible health condition which is mainly treated at home. As such they are unique candidates for support via telehealth services. During the last 20 years, a number of ICT interventions have been deployed to support renal disease. This paper reviews current trends in home care telematics for patients on peritoneal dialysis and comments on certain design considerations that prohibit the widespread deployment of such services. Whenever pilot studies have been performed, these report user acceptance, increased quality of life and even better health outcomes. Interest in the area is expected to rise as the population with renal disease is increasing. Despite this, the extent of development and maturity in renal telehealth is rather limited, when compared to other telehealth applications. This paper argues that this low technology penetration is mainly due to the fact that current approaches are treatment- and disease-centric, do not integrate patient education and tools for overall disease management. Additionally current trenal telehealth services do not follow open, standard based software development principles and are inadequately evaluated. The paper concludes with specific proposals to alleviate these problems.**

1. ***Keywords***— home care telematics, renal telematics, telemonitoring, patient management.

I. INTRODUCTION

Nowadays, the number of renal disease patients tends to increase, mostly due to the increased incidents of diabetes and hypertension. Chronic kidney disease may lead to several and often severe chronic complications such as arterial hypertension, nephrogenic anemia, renal osteodystrophy, peripheral neuropathy, malnutrition as well as cardiovascular disease, and eventually death. Thus early detection and treatment can often maintain renal function before chronic kidney disease deteriorates to end stage renal disease and renal failure. However, this is not always possible and the disease progression may eventually lead to kidney failure and the fact is that the number of end-stage renal disease patients tends to increase [1]-[3]. It is therefore becoming all the more imperative to take measures for the prevention and the better management of end stage renal disease. Indeed, in various categories of renal patients close monitoring may prove a good measure for early diagnosis, treatment adjustment and rehabilitation.

Specifically, for patients with chronic renal failure, there is a need to follow up any unexpected exacerbation of the renal function in order to prepare for kidney replacement therapy (dialysis or/and transplantation). Especially patients with chronic systemic diseases such as diabetes, hypertension, as well as patients older than 60 years should be carefully evaluated not only to estimate the time for introducing renal replacement therapy but to avoid any undesired exposure to drugs or procedures associated with acute decline in kidney function.

For patients on peritoneal dialysis, success of their treatment method depends on the dialysis scheme which is designed by the doctor for each individual patient and is determined among else by physiological parameters such as: patient weight, blood pressure and heart rate (and in specific cases ECG and blood glucose), as well as the type and amount and the daily frequency of the peritoneal solution exchanges that are required in order to succeed an adequate fluid and solute removal during dialysis. Abnormal alterations of these parameters, if detected on time, may prevent severe side-effects such as oedema and acute dehydration. Proper inspection of catheter exit site is also important to prevent and/or timely detect peritonitis.

For patients on hemodialysis, there is substantial evidence regarding correlation between the delivered dose of hemodialysis and patient morbidity and final outcome. Since clinical signs and symptoms are not reliable indicators of HD adequacy, the delivered dose should be measured and monitored routinely. Formal kinetic modeling provides a quantitative method for developing a treatment prescription for a specific patient. Regarding the dialysis session duration, some clinical researchers argue that the hemodialysis treatment time alone, independent of dialysis adequacy indices, can be used as a measure of the hemodialysis adequacy. Today there are several HD methods that may easily serve the special patients needs for fluid and solute removal.

For patients on a wait-list for transplantation, vital signs and other overall health condition monitoring ensures the patient's condition is always adequate for undergoing transplantation.

Finally, for transplanted patients, there is a special need for systemic careful evaluation both for adequate kidney function as well as for the avoidance of any inflammatory and other possible factor that may be threaten the patient's health. Ensuring adherence to prescription is also important.

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In addition to the above, regular interaction among the healthcare provider and the patient ensures adherence to treatment specifics and dietary style/prescription, while it supports psychologically the patients and their families.

II. Current state of the art

Information and communication technologies (ICT) can be (and have been) employed to support the management of renal patients. During the last 20 years, a number of ICT interventions have been deployed to support renal disease. These are mainly organized in two broad categories: (a) teleconsultations and virtual home visits, and (b) telemetry of related data. Early experiences mainly in USA [4] and Australia [5] concentrated on videoconferencing for hemodialysis. Around the year 2000, Europe [6] and Japan also showed interest in this area, and at the same time videoconferencing began to support PD as well [7],[8]. Recently, telemetry of cycler data and other related biometric parameters and vital signs enter the scene, mainly for PD home monitoring [9]. Recently, both leading companies in dialysis equipment, Fresenious Medical Care (Germany, http://www.fmc-ag.com/) and Baxter International Inc. (IL, USA, http://www.baxter.com/), have incorporated telemedicine in some of their peritoneal dialysis cycler models, allowing data transmission via modem, as well as live patient-physician interaction. Literature reports very limited clinical use of these cycler embedded telemedicine application - in Italy the employment of Fresenius telematic–enabled cyclers in 2002 and 2003 [10], [11], and in the USA the employment of Baxter telematic–enabled cyclers in 2008 [12]. To allow ubiquitous monitoring of peritoneal dialysis irrespective of cycler provider, two different services have been recently deployed in Europe. In France, the DIATELIC project [13] puts emphasis on monitoring telemetry data as this is given manually by patients. In Greece, the PERKA service [14] is the only fully web-based service, that allows for dynamic service configuration by the medical personnel to account for unforeseen data monitoring needs.

A review of current state in the field shows that monitoring of the condition of the renal patients (either by teleconferencing or via data telemetry) may have positive effects and improve quality of life and health. Indeed, the fact that renal patients are treated mostly outside the hospital while maintaining at some degree their normal activities, combined with the fact that regular monitoring and management of their treatment and overall health condition is clinically meaningful and desirable, make the renal patient a unique candidate for support via telehealth services. Whenever pilot studies have been performed, these report user acceptance, increased quality of life and even better health outcomes. Interest in the area is expected to rise as the population with renal disease is increasing. Most importantly, such monitoring services may prove invaluable for patients and healthy citizens at risk of developing end stage renal disease, and for monitoring the health level of patients on a wait-list for transplantation. Despite this, the extent of development and maturity in renal telehealth is rather limited, when compared to other telehealth applications.

III. Problems and requirements currently unmet

We argue that major reasons that may lead to this low technology penetration include the following.

Current approaches are treatment-centric, that is, their goal is the monitoring or consulting of either hemodialysis or peritoneal dialysis. However, the health care goal is the management of the renal patient, who may switch between treatments. A patient on PD awaiting transplantation may finally get the graft and then should be closely monitored in a different manner to ensure recovery and reduce rejection probability. Or, a patient on HD may change to PD and vice versa, etc. However, current solutions do not provide continuity of monitoring and care for the renal patient, irrespective of treatment.

Current approaches are disease-centric rather than being personalized and human-centric. They emphasize on the dialysis and other medical parameters, in order to monitor the disease and treatment process, and create appropriate alarms and decision support to support doctors. However, renal patients are chronic patients that live with their condition for their entire life. They live in their own environment, most of the time outside the hospital, and they usually pursue (or try to pursue) a normal life. Indeed, most of the effort in state-of-the-art advancements in treatment methods aim at promoting a mobile patient in their own environment. It is only natural that the ICT intervention should take into account the patient at their own environment leading their life, in addition to being treated and monitored for renal disease.

Current approaches are ‘data-centric’, in the sense that emphasis is on transmitting and processing medical data, while renal patients are often greatly overlooked. Indeed, confronting a chronic, irreversible condition mainly treated at home, renal patients and their families comprise one of the few patient groups that mostly need support for self management, continuous education and training, social support and networking.

Moreover, current approaches are clinically oriented, putting emphasis on supporting medical personnel to manage the health condition of the individual. However, in renal disease a major challenge is the overall management of the chronic renal disease (not only the patient) including planning and management of dialysis centers, organ donation, matching and transplantation and overall management of related resources and financial issues.

On the technical side, current approaches at a great majority are closed, proprietary solutions created by a single vendor, not allowing for any interoperability among third parties. From the patient to the center and the data processing, current solutions are developed by a single vendor without standard interfaces for interoperability with other products. Should a health care institute decide to deploy such a service they would have to stick with the same provider for all desired functionality.

Finally, current approaches, when evaluated, are regarded either as technological interventions or as 'drugs' for patients to use in order to improve their health condition. Moreover, often evaluation is treated as an unavoidable project aftermath, rather than a learning process to improve and appropriately tailor the intervention at question. It is most likely that such systems eventually fail to fulfill expectations and thus fail to become useful and indispensible.

IV. PROGRESS BEYOND THE STATE OF THE ART

In order for information and communication technologies to provide efficient, effective and sustainable support for the renal patient the following must be taken into consideration.

Thorough field analysis and research should be conducted to identify and model context in the case of renal patient management. Renal patient context encompasses issues from the social and health environment, as well as context related to the patient and the medical personnel. Renal patients, mostly treated as outpatients, are strongly interfering with their normal social environment, while at the same time they interact with the healthcare environment to address their chronic condition. The patients themselves have their individual characteristics, preference and overall situation that define their own context. On the other hand, their healthcare providers being individuals as well as professionals exhibit their own personalized perspective. Thus, research should target to develop four strongly interlinked ontologies: (a) a patient ontology, (b) a social environment ontology, (c) a healthcare professional ontology, and (d) a healthcare environment ontology. These ontologies can then be used to build context aware renal telematics services, which may include context aware patient monitoring, context aware medical intelligent alarms, context aware patient feedback and education and context-aware health provider decision support.

In order to support personalized self management, renal telematics should also make provisions for patient education and social networking. Here the active participative nature of web 2.0 paradigm should not be overlooked. Moreover, the enormous penetration of applications such as social networks and virtual worlds gives a unique opportunity to support networking of renal patients, and to promote public awareness on issues pertaining to renal disease prevention and organ donation. Thus, a renal telehealth service should also include access to such supportive functionality and, even more, allow feedback from social environments to reach the health care professional.

Additionally, the healthcare professional and the administrator should have access to advanced tools for monitoring not only the individual but the entire renal patient population and all related resources used for renal disease management. In this respect, renal telematics services should be coupled with population and disease management simulation tools, with bi-directional flow of data. That is, continuous real monitoring data should be the input to decision support tools for overall population management, while the output should be directly used for the management of the individual via renal telemedicine.

From the technical perspective, renal telemedicine systems and services should be designed and developed following service oriented architectures and abiding to international, preferably open and generic, technology standards. A service-oriented architecture (SOA) offers system design and management principles that support re-use and sharing of system resources across the healthcare organization. Respective systems should follow a principle of developing and combining core (web) services with generic standard interfaces for communication and data exchange amongst them, so as to allow for seamless integration of third party applications. Competitive development of similar components by third parties should be promoted. We believe that the existence of a number of competing solutions is for the advantage of the end user as well as for the advancement of the market itself. Moreover, each prospective researcher/developer in the area should not have to 'reinvent the wheel' by designing and building yet another integrated telehealth system. Rather, they should concentrate to develop the component that best fits their expertise and use an overall service oriented architecture to plug in their component and integrate with the overall telehealth application.

Finally, pilot renal telehealth projects should invest on sustainability studies. There is an agreement that the evaluation process of home telehealth services is much more complicated than that of the rest telehealth applications [15], mainly because of the nature of stakeholders and the context of home telehealth interventions, and the engagement (or lack of) patients in the design process. Indeed, the most common reason mentioned is the diverse group of stakeholders. Stakeholders come from different parts of the healthcare system with different value systems, different perceptions of risk and different expectations of the home telehealth application. Costs and benefits may fall unequally between the various groups of stakeholders. The second reason that is seen often in literature is the diffused context that home telehealth is applied to. The surrounding context varies (each patients' home) and given the fact that home telehealth applications are few and short (in terms of pilot applications duration) makes it difficult to generate data of sufficient scope and scale for conducting a careful analysis. These obstacles require careful consideration of the evaluation approach to be used, which should follow a holistic, interpretive paradadigm. Rather than go into randomized control trials and calculate cost benefit, the main objective of an evaluation approach should be to provide feedback for developing and deploying a meaningful and socially acceptable telehealth intervention. A renal telehealth intervention should be viewed neither as a medical innovation nor as a drug that can be prescribed to patients, but instead it should be viewed as an information system/service coming to serve information transmission and processing needs in a specific complex environment with a variety of actors in different context. Such actors include the service itself, the humans involved (patients, healthcare providers, and administrators) and the society in general (the social environment and the healthcare system). For all these actors, the evaluation process should address issues of structure, process and outcome alike [16].

In order to produce a telehealth service that is usable, meaningful, and beneficial to patients, health institutions and more generally to society, the technical intervention should be technologically viable, socially acceptable and institutionally feasible, and thus sustainable. Towards this objective, renal telehealth research and development should strive to develop patient-centered services for seamlessly supporting the renal patient across treatment methods, health centers and living environments, as well as different environmental/personal conditions, integrated with social and educational services as well as with overall disease management tools.

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