Improving quality of life for dialysis patients through telecare

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Summary

Home dialysis can improve the care and quality of life for patients with renal failure. We have explored the possibility of extending home care to more patients needing continuous ambulatory peritoneal dialysis (CAPD) using telemedicine. We tested videoconferencing support for five CAPD patients using low-cost ISDN equipment (128 kbit/s). Initial results indicated that it was possible to integrate video-communication into the daily routine of the clinic and the response from patients was surprisingly positive. Selection of appropriate, affordable technology and the ISDN service support by the telecommunications provider proved to be considerably more difficult than anticipated. The first indications also suggest medical advantages for home teledialysis.

Introduction

Almost a million individuals in the world and more than 200,000 in Europe suffer from chronic renal failure. Of these, more than 800,000 patients in end-stage renal failure are dependent on dialysis. Because of the ageing population and medical progress in coping with diseases causing renal failure, the prevalence is increasing at an average of 8% per annum. The combined value of the global market for renal care products and renal care services is estimated at about 27 billion euro, of which treatment accounts for about 21 billion and renal care products for about 6 billion euro (1 euro is $1.05).

Research has shown that home dialysis can improve medical care for patients[1]. In addition, more flexibility allows for many patients – particularly peritoneal dialysis patients – a better adaptation both to a changing work environment and to leisure activities, which in turn translates into a higher quality of life. In addition, there are reports that home dialysis (be it haemodialysis or peritoneal dialysis) leads to a reduction in overall treatment costs[2].

The KfH Kuratorium fuer Dialyse und Nierentransplantation (KfH Board for Dialysis and Kidney Transplantation) is a not-for-profit organization in Neu-Isenburg which was founded in 1969. It services more than 15,000 dialysis patients (of whom 2250 are on home dialysis, mostly peritoneal dialysis) in 188 clinics. The extension to home dialysis is a priority. The Frankfurt/Main clinic services 225 dialysis patients, of whom 180 are on haemodialysis being treated on the premises and 45 home dialysis patients on continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis.

The aim of the pilot project was to explore the possibility of improving home care for dialysis patients (initially only for CAPD patients) by adding video-based support[3]. If successful, this would then lead to the extension to haemodialysis for home patients, and allow those who for various reasons do not undertake home dialysis to consider it. The expected benefits include a gain in quality of life for these patients, cost savings for the health system and a competitive advantage for the clinics involved.

Methods

The project implementation began in January 1999. At the start, in an iterative discussion process between doctors, nurses and project management, we clarified the shorter-term expectations (Table 1) and longer-term benefits hoped for (Table 2).

Based on these expectations and a detailed analysis of patient service processes, a model for the video-service was developed to serve as a framework for subsequent implementation. In preparation for

Table 1 Expected short-term benefits from video-communication

Medical aspects	Better compliance monitoring (hygienic precautions) Fluid (peritonitis) control Catheter exit-site inspection Environmental check Check on psychological condition
Technical aspects	Assistance in handling of peritoneal dialysis equipment
Patient aspects	Improved security/self-confidence Better quality of life
Risks	Training and other additional burdens The need for seamless organizational integration into daily routines Quality and reliability of technology

Table 2 Expected long-term benefits from video-communication

Medical aspects	Fewer cases of peritonitis Fewer other complications/ hospitalizations Better control of other diseases
Technical aspects	Application of advanced peritoneal dialysis equipment Implementation of automatic transfer of vital data
Patient aspects	Fewer visits (time and cost savings) Lower threshold to the use of home dialysis
Impact on clinic	Improved general services/competitive advantage Cost reduction/better time management

this pilot service, we identified related activities abroad and took into account their experience when appropriate information was available and applicable to our situation. A very useful account was an unpublished paper, 'Evaluation of renal telemedicine to the home', which reports a three-month experiment with a single dialysis patient over a distance of 320 km in Australia[4]. The US Project Phoenix concerns a different situation – a telemedicine connection between a main and two remote haemodialysis sites[5]. A similar situation seems to exist at the Orillia Soldiers' Memorial Hospital[6] in Canada and the US Austin-based Moncrief Dialysis Center[7].

Equipment

We tested various equipment configurations. There were several constraints, such as the need for the equipment to be easy to handle and robust, for video-phones and cameras which can be preset so that the patient need not touch them (because of hygienic precautions), for high picture quality even under changing lighting conditions, limited table space for positioning the equipment in the dialysis room/corner of the patient's home and, not least, acceptable costs. We finally selected a standard ISDN video-phone (128 kbit/s) (T-view 100, Deutsche Telekom). It had the best codec of its type and by connecting it to a standard television screen in the service centre and to different types of cameras in the homes of the patients we obtained good video quality.

We also tested a television set-top box ISDN video-phone and a stand-alone codec, but they did not produce better results. We did not test any PC-based equipment because of the problems anticipated when inexperienced, handicapped patients have to handle it. It was also more expensive.

Implementation

We involved physicians and nurses in the clinic to obtain their assessments, to implement their requirements as far as possible and to train them. For the last purpose, a second video-phone was installed in another consulting room to simulate the situation when calling a patient. Subsequently this also served to demonstrate the system to patients. At the end of this process, the complete project team met in the clinic to discuss the experience, assess the results obtained so far and to decide on the next steps.

After developing a handbook for patients, as well as forms for meeting legal requirements and cost aspects, a patient was selected to gain initial experience in the real-life handling of the equipment and in integrating the video-service into routine operations. Subsequently, four more patients were connected. Patients were selected either directly by clinic staff or themselves asked to participate.

Video-phone calls were made weekly at a predetermined time. Each call was recorded on a protocol form which registered information concerning, for example, vital signs, purity of the dialysis fluid after drainage (which was controlled by the nurse via the camera and a test paper put underneath the dialysis bag by the patient before the call), check of the catheter exit site in the peritoneum of the patient, handling of bag exchange as needed, non-dialysis-related medical questions, drugs taken or needed, any other problems, date and time of next video-call or visit to the clinic (usually once per month), problems with the video-equipment and, if needed, alerting of the technical service.

The effect on the patients' quality of life[8,9] is being measured by the Kidney Disease Quality of Life

Short Form (KDQoL-SF, Version 1.2), which is available in German. In addition, based on a structured guide, patients are being interviewed about their subjective expectations and assessment, and technical problems encountered a few weeks after their initial involvement and after six months. The same applies to the physicians and nurses. Because of the size of the sample and the selection of patients, the results will be purely qualitative.

Results

Initial impressions indicate that patients – after a short phase of training and adjustment – do not have any major problems in handling the equipment or in engaging in video-communication. They seem to be happy about this additional means of contact, stress that it gives them additional security, and in one case also experiment with it by connecting their own (privately owned) video-camera, which led to a much better picture quality. However, at this stage of the project we must stress that only longer-term results with more patients will allow a more reliable assessment. The present project will end early in 2000, but it is anticipated that the service will be continued and expanded to more patients in the context of a follow-on activity. This will also involve testing of newer, more advanced video-equipment.

Discussion

The initial clinical evaluation indicated that such a service could be very useful:

(1) for insecure patients or those living alone, particularly during the transition phase from hospital (after implantation of the catheter) to the home, and in coping with their very individual hardship and anxiety;
(2) for the exchange of experience and consultations among smaller, less experienced centres and with a larger clinic.

The tests also showed that fluid control can be performed with a relatively cheap external camera, whereas a medical inspection of the catheter exit site requires a higher-quality camera with automatic exposure control. It appears that a standard mid-priced amateur video-camera (costing about 1000 euro, where 1 euro is $1.05) will suffice once more experience has been gained in assessing the video-pictures over an extended period.

The organizational aspects did not cause any major problems. Learning and training efforts were acceptable, and the integration into organizational routines was easily realized. Equipment was placed on an existing desk in the major consulting room without disturbance of other activities. Calls were usually scheduled on days when no CAPD patients were present, so the privacy of the patient was protected. Patients were advised not to call in unless in an emergency.

The technical aspects caused more problems and were far more time-consuming than anticipated. The difficulties did not concern the routine operation of the system, but the initial steps of establing the patients' ISDN connections and defects in newly purchased equipment. The software of the ISDN exchange in the clinic had to be reloaded, some video-phones had to be returned because of malfunctions, the ISDN connections were not installed on time, telecom service appointments at the patients' home were not kept, and information given to patients by service representatives was contradictory. For a routine clinical service, the resulting costs in professional time wasted and the annoyance of patients are simply unacceptable. We hope that both increased competition in the telecommunications sector and our learning-by-doing will lead to improvements.

We believe that the pilot trial will help to identify opportunities to improve the quality of care and the quality of life of many home dialysis patients. As more experience is gained and the costs of equipment and telecommunications diminish, we hope to establish a business case to allow the wider implementation of such a service and to extend it to patients for whom home dialysis has been beyond reach.

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