MEDINFO 2007
HISA Ltd Australia
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Facilitating Hospital-at-Home Therapy Through Advanced Remote Patient Monitoring

Joseph A. Cafazzo[ac], Peter Picton[a], Jack Lam[a] Peter G. Rossos[ab], Anthony C. Easty[ad], Kevin Leonard[ac], Christopher T. Chan[b]

[a] *Centre for Global eHealth Innovation, Toronto General Hospital, Canada*
Faculty of Medicine, University of Toronto, Canada
[c] *Health Policy, Management and Evaluation, University of Toronto, Canada*
[d] *Institute of Biomaterials and Biomedical Engineering, University of Toronto, Canada*

Abstract

Resource shortages in the healthcare system has called into question its sustainability and has generated interest in alternative forms of service delivery. Delivering of complex services in the home at a lower cost and with improved outcomes has proven to be elusive. In this study, we discuss the development of a comprehensive remote patient monitoring system that facilitates self-care of nocturnal hemodialysis patients, a complex hospital-at-home therapy. An ethnographic analysis was undertaken, determining the barriers to adoption and design criteria for a system that would facilitate mediated patient self-care for a complex therapy. These data were then used to inform the development of a remote patient monitoring system. In our pilot testing, patients developed a dependency on the system, when it was expected to be needed only for their transitional phase. Patient accountability was increased through the use of the system when it was found that patients did not always dialyze as frequently as they reported. The development of a blood disconnect monitor proved to be a critical component of the system. The resultant system provided an increased level of comfort and reduced anxiety for patients, and for family caregivers in particular.

Keywords:

monitoring, ambulatory; hemodialysis, home; self care

Introduction

End-stage Renal Disease (ESRD) is a complex medical illness that is becoming more prevalent. Estimates of increased prevalence are as high as 7.5% per year. [1] The most common form of renal replacement therapy for ESRD is hemodialysis (HD), a costly, resource – intensive therapy that artificially sustains renal function, but can also contribute to a poor quality of life. The present form of therapy is what the health system can afford to deliver and what a patient can tolerate in terms of disruption to their lives. This treatment pattern is mostly a systemic limitation of the delivery of healthcare services, rather than what is medically efficacious for the patient.

Nocturnal hemodialysis (NHD) is essentially a more frequent form of the therapy, delivered for longer periods of time, as the patient sleeps at home. The improved health outcomes are dramatic. Patients enjoy improved cardiovascular health, improved peripheral circulation, improved sleep quality (despite undergoing dialysis treatment), and the elimination of dietary restrictions. [2, 3] Patients experience greater autonomy by being freed from institutional care. Despite the capital costs of providing a dedicated hemodialysis machine to a patient, the cost-effectiveness of NHD is clear when factoring in the greatly reduced nursing care and the reduction of medications. [4]

Although NHD has been shown to provide significant improvements in health outcomes and improved resource utilization for the health care system, the adoption of the therapy has been slow. NHD would require major changes to the way dialysis programs are delivered.

Beyond these systemic problems, there exist patient-related barriers to the adoption of NHD. Patients fear they will fail to perform dialysis adequately. They also fear that they will receive substandard care and that they will be socially isolated. [5]

Given the significant improvement of health outcomes associated with NHD, it is important that a means to reduce and overcome these barriers be developed to improve adoption.

To address these barriers, we proposed a method of supporting the patient in performing NHD by means of a virtual support system, replacing an aspect of the nursing support they received in the conventional setting. This will take the form of a remote patient monitoring system, which will relay vital signs and dialysis treatment parameters to hospital staff, which in turn, can act on information received as needed.

It is hypothesized that patients will have less anxiety and perceives greater self-efficacy with the notion of this support. This may lower the barrier to adoption of NHD as a therapy option. In addition, family members are also hypothesized as being more supportive of NHD therapy

with the inclusion of remote patient monitoring. There is some evidence that home hemodialysis adds a significant burden to family members [6]. Ultimately, the goal of the system is to have the patient reach a level of "supervised autonomy" in performing their therapy.

Research question to be addressed was "What specific design criteria must be met by the system, such that the patient will accept the system and feel that it contributes to their overall security and confidence to perform NHD?"

Methods

The assumptions of the use of remote patient monitoring as an intervention to reduce the barriers to the adoption of NHD were challenged through the use of patient-centric design method, beginning with ethnographic interviews of dialysis patient groups (nocturnal hemodialysis (NHD), conventional hemodialysis (CHD), and pre-dialysis patients). Specific data was gathered to inform the first iteration of the system development.

The number of informants used in the study was to be determined when sufficient saturation was achieved. In the end, saturation was achieved with seven patients in the NHD group, and six patients in each of the CHD and pre-dialysis patients groups.

A general inductive method was using in the analysis of the transcripts. Transcripts were read repeatedly and text segments were coded for potential themes. As the coding framework developed, transcripts were reanalyzed in light of new themes that may have emerged as a result. Once completed for a specific treatment group, major themes were derived that were relevant to the research question. Qualitative analysis software was used to code the interviews for emerging themes. These findings were then validated through a member-checking exercise with a focus group of NHD patients and family caregivers.

These data then informed the development of design principles. The purpose of these design principles was to guide the engineering team in their deliberations around specific functionality and design aspects of the system. In some sense, these principles become a rulebook for the engineering team, in which assumptions that are made through the course of development are tested against these principles to ensure adherence. Violations of these principles will likely result in a sub-optimal system and would no longer be adhering to a user-centric method of design.

Once implemented after a number of iterations, a small pilot study of eight patients were monitored for 3 to 10 months. Interviews of the patients were performed throughout the pilot to determine the outcomes in terms of perceived safety and facilitating adoption and adherence to NHD.

Results

Without exception, all the participants found the concept of remote monitoring for NHD patients as a positive development, although there were significant differences of opinion on specific aspects. There was varying opinion on the patient-type which remote monitoring should be applied to, as well as the duration, form, function, and purpose of the technology.

- Patients already had an expectation of the use of remote monitoring. Some patients presumed it was already in place and that they were to receive it upon installation of the machine in their home.
- Patients supported the transitional use of remote monitoring. Although some patients felt they required some form of monitoring on a permanent basis.
- Patients had varying levels of need for remote monitoring. From no monitoring to all, to monitoring through the transition, to a permanent installation. As well, patient had varying needs in terms of specific components of monitoring.
- There was some concern over privacy and the "Big Brother" effect of using remote monitoring. Patients expressed concern over the detailed knowledge their caregivers would have of the schedule, frequency and habits when dialyzing at home.
- Use of a camera was suggested by patients, and would be used by minority of patients. They viewed its purpose as useful for trouble-shooting as well as for safety.
- Remote patient monitoring is particularly supported by family-caregivers and is viewed as a surrogate to nursing care. Family caregivers viewed it as a backup, or safety net for themselves to reduce their anxiety and to address what they perceive as a lower level of care in an emergency, than what they would receive in-centre.
- There is concern by the patients of the physical obtrusiveness of monitoring and that this would produce adherence issues. Patients are concerned how further tethering themselves to the machine will affect their sleep and the mobility when addressing alarms.
- The suggestion of the use of wireless monitoring was well received and may address the issue of the obtrusiveness.
- The need for monitoring the integrity of the bloodlines was identified, as potential blood loss one of the most significant fears amongst patients.
- Patients were comfortable with the use of automation for alerting caregivers in an emergency. However, they expressed a need for human intervention in immediate response to this alerting.
- Pre-dialysis patients, unfamiliar with the process of hemodialysis, expressed concern over the need for

monitoring. Unless the patient is already aware of the risks involved in performing hemodialysis, patient may become alarmed at the need for monitoring.

Design principles

Based on these findings and the detailed themes as discussed above, the following design principles were developed:

1. The physiological sensors will be unobtrusive as possible to the patient, allowing them freedom of motion and will not be uncomfortable so as to interfere with their sleep.
2. The system will not add to the training requirements of the NHD patients.
3. The system must communicate more than just the status of the dialysis machine.
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5. The system will allow for transitional monitoring, such that installation can be done quickly and removed equally so.
6. The system will be entirely automated from the patient's perspective, leaving them only to apply the physiological sensors as necessary.
7. The patient will have the option to decline the use of any or all of the components of the system, including the camera, so as to respect their privacy and to meet their individual needs.
8. The system will address the need for ensuring bloodline integrity, without adding to complexity of the existing setup.
9. Automated alerting will result in direct contact by the caregiver-on-call to the patient. The system should scalable to allow a call-centre approach to addressing these alerts.
10. Data acquisition and transmission will be done securely and will comply with the standards of the healthcare organization and relevant legislation.
11. The system will be modular, where components can be removed and added as needed or appropriate.
12. The system architecture will be generic and abstracted, so that interfaces to other devices can be easily added as needed.The system will not add significantly to the cost of NHD delivery, be scalable, and will leverage existing data infrastructure.
13. The system will work within the existing workflows of the current NHD program.

These use of these design principles resulted in an initial system design consisting of the acquisition, transmission, storage, and processing of patient vital signs (heart rate, respiration rate, blood oxygenation, and blood pressure) and selected hemodialysis treatment parameters of the hemodialysis systems. Rules were developed through discussions with domain experts including nephrologists, nursing staff, and renal technologists. These rules would be applied to the data in real-time and alerts generated. In the first iteration of the system, these alerts would be sent to on-call staff who will receive the alerts and assist the patients as necessary. See figure. below.

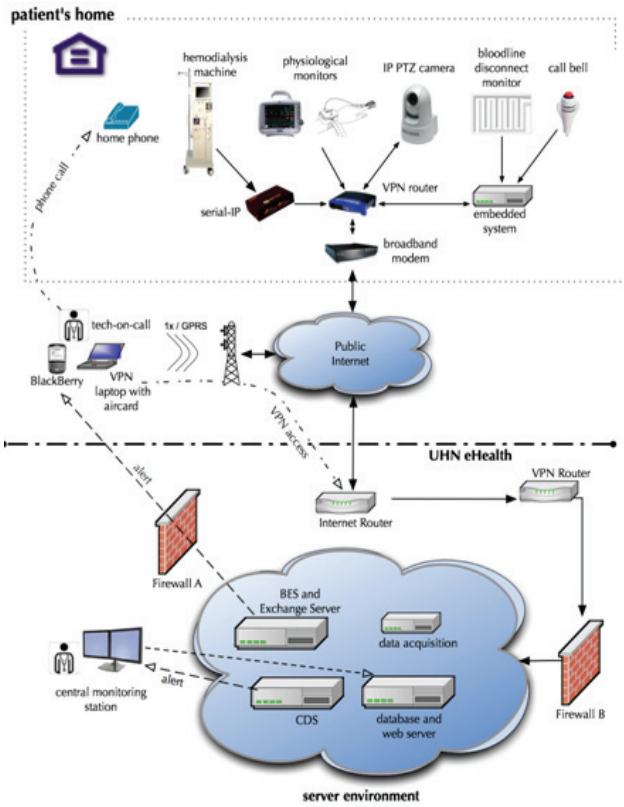

Figure 1 - UHN HEalth

Additional components included an IP-based pan-tilt-zoom (PTZ) video camera, to allow staff to observe remotely at the patient's discretion. This would aid in remotely troubleshooting the dialysis machine as well as have the ability to check on a patient during a serious alarm condition.

Also developed was a bloodline disconnection detector, utilizing a liquid-sensitive pad that would lie under the

patient and trigger an audible alarm if blood were to come into contact. The detector also cuts power to the HD machine, disabling the blood pump and stopping further blood loss. An IP-based message is then sent back to the technologist-on-call to notify them of the event. Incorporated into the system, was a patient call bell system. Much like the systems found in an in-patient setting, patients could simple press the call-bell button to alert the on-call staff via IP messaging.

The clinical decision support component of the system generates alerts based on criteria being developed by domain experts. These alerts are sent to the technologist-on-call through a mobile communication device. The alerts contain relevant information, current patient vital signs, and the patient's home phone number for quick access via the device's telephony capability. For further follow-up to the alert, the technologists can VPN into the system, access more physiological and dialysis data, and take control of the IP camera if necessary.

A clinical pilot of eight patients has been underway since January of 2006 and refinements to system are being made through feedback from clinicians and patients. Preliminary analysis of this phase of the study has found the following.

- Patients develop a dependency on the system, despite initially expecting only to need the monitoring during their transition. Particular aspects of the system they feel they cannot do without, including the bloodline disconnect monitor and the call-bell.
- The incidence of bloodline disconnects appears to be higher than is commonly reported. One incident occurred after only 3 months of deployment with only four patients being monitored.
- One patient felt that their privacy was being invaded when the nursing staff would challenge them on the frequency and duration of their dialysis. The patient was not adhering to what was prescribed and was alarmed that the hospital was aware of this level of detail in treatment information. This incident has demonstrated an added a level of accountability for patients that are being monitored that did not exist before. This has resulted in concern that patients are not adhering to their prescribed treatment levels and are therefore not fully benefiting from the therapy. The negative aspect of this finding is that use of the system in this manner could lead to trust issues between patient and provider, harming this relationship.
- Adherence to the use of vital signs monitoring remains a challenge, as patients are still fatigued using wireless sensors that are uncomfortable and interfere with their sleep and range of motion.

Conclusion

The study demonstrated the use of a patient-centric design method to facilitate the adoption of a hospital-at-home therapy. Therapies such NHD, which has been shown to deliver improved outcomes at lower costs, are vital for the future sustainability of the healthcare system. The delivery of hospital-at-home services will likely require some form of remote monitoring to mitigate risk and to improve patient adoption. A patient-centric approach to the design of this system has permitted the development of a scalable and flexible remote patient monitoring system to allow other hospital-at-home applications including CHF, chemotherapy, TPN, and palliative care.

Acknowledgments

This research was funded through a grant provided by Bell University Labs at the University of Toronto.

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Address for correspondence

Joseph A. Cafazzo, Centre for Global eHealth Innovation, Toronto General Hospital, University Health Network, 190 Elizabeth Street, R. Fraser Elliott Building 4S400, Toronto, Ontario, Canada M5G 2C4,
Email: oe.cafazzo@uhn.on.ca