

Bridging the Self-care Deficit Gap: Remote Patient Monitoring and the Hospital-at-Home

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Abstract. This study examines the use of a remote patient monitoring intervention to address the challenge of patient self-care in complex hospital-at-home therapies. It was shown that in a home hemodialysis patient group, remote patient monitoring facilitated self-care and was supported by patients and, in particular, family caregivers. This does not come without cost to the patient however, who now has greater personal responsibility and accountability for their health management. Promising results from this study indicate that most patients are willing to assume this cost in exchange for the possibility of improved health outcomes.

Keywords: Self Care, Telemedicine, Monitoring, Physiologic, Telemetry, Hemodialysis, Home.

1 Introduction

Chronic disease is one of the foremost problems facing the sustainability of healthcare systems globally [1]. New cost effective models of care delivery are urgently needed. There are emerging data that support the effectiveness of a systems wide approach of chronic disease management first described by Wagner [2]. The fundamental premise of the model is to dismantle traditional silos by aligning all activities of the health system to support productive interactions between informed, activated (i.e., empowered) patients and a prepared, proactive practice team across the delivery continuum. This model assumes that self-management support strategies will enlighten and empower the consumers, and clinical information systems, and decision support tools will enhance the clinical encounter.

One group that could benefit from this approach is hemodialysis patients. End-stage Renal Disease (ESRD) is a complex chronic condition that is becoming more prevalent, increasing as much as 7% per year [3]. Hemodialysis is a costly resource

intensive therapy that artificially provides renal function, but can also contribute to a poor quality of life. Home hemodialysis is a simple variant of conventional hemodialysis. It is potentially a more frequent therapy, delivered for longer periods of time, even as the patient sleeps. This requires the patient to dialyze at home with their own dialysis machine; a true hospital-at-home intervention. The improved health outcomes are dramatic. Patients enjoy improved cardiovascular health, improved peripheral circulation, improved sleep quality, and the elimination of dietary restrictions [4, 5]. Patients have been shown to experience greater autonomy by being freed from institutional care. However, there exist patient-related barriers to this form of self-care. Patients worry about the burden on family members, fear the self-cannulation, fear for a catastrophic event, and have low self-efficacy [6].

To address and facilitate patients performing home hemodialysis, a remote patient monitoring intervention was proposed. A user-centric design approach was used in the development of the system [7]. In keeping with this approach, an ethnographic analysis based on Health Belief Model framework [8] was undertaken, determining the barriers to adoption and design criteria for a system that would facilitate mediated patient self-care.

The purpose of this study component was to determine the net effect of this remote patient monitoring on a patient's ability to perform self-care and how it would contrast with the conventional nurse-patient relationship.

2 Methods

A pilot trial of the remote patient monitoring was conducted with eight patients consisting of seven men and one woman, from 22 to 60 years of age. The average age was 46. All patients were new to home hemodialysis treatment. Patients were monitored from between 6-15 months. Semi-structured interviews were conducted with each of the eight study participants. Each participant was interviewed on at least one occasion. The maximum numbers of interviews were three. The numbers of interviews were based on patient availability and when data saturation had occurred. The patient interview script was structured in the following manner; general impressions, pros and cons of the system; impact on well-being, stress, ability to cope, if any; interactions with clinical staff as a result of the use of the system; need for the system going forward; impact on family members. Nursing interviews followed a similar structure where relevant, and had the additional line of questioning relating to: impact on workload; impact on patient care; impact on their role as nurse/technologist. Four staff nurses from Toronto General Hospital, University Health Network Home Hemodialysis unit were interviewed. These are the same nurses who trained the patients and participated in the study by reviewing the dialysis summaries generated by the intervention. Once a sufficient level of saturation was achieved in the interviews, the recordings were transcribed verbatim from audiotape.

Analysis. 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. Coding was not limited to the evaluation

objectives and was free to not assume any presuppositions. NVivo qualitative analysis software was used to code the interviews for emerging themes [9].

Description of Intervention. The system consisted of the acquisition, transmission, storage, and processing of patient vital signs (heart rate, blood oxygenation, and blood pressure) and selected hemodialysis treatment parameters of the hemodialysis machine. Rules were developed through discussions with domain experts including nephrologists, nursing staff, and renal technologists. These rules were applied to the data in real-time and alerts generated. These alerts were sent to an on-call technologist staff who received the alerts and assisted the patients as necessary. Additional components included an IP-based pan-tilt-zoom (PTZ) video camera, to allow staff to observe remotely at the

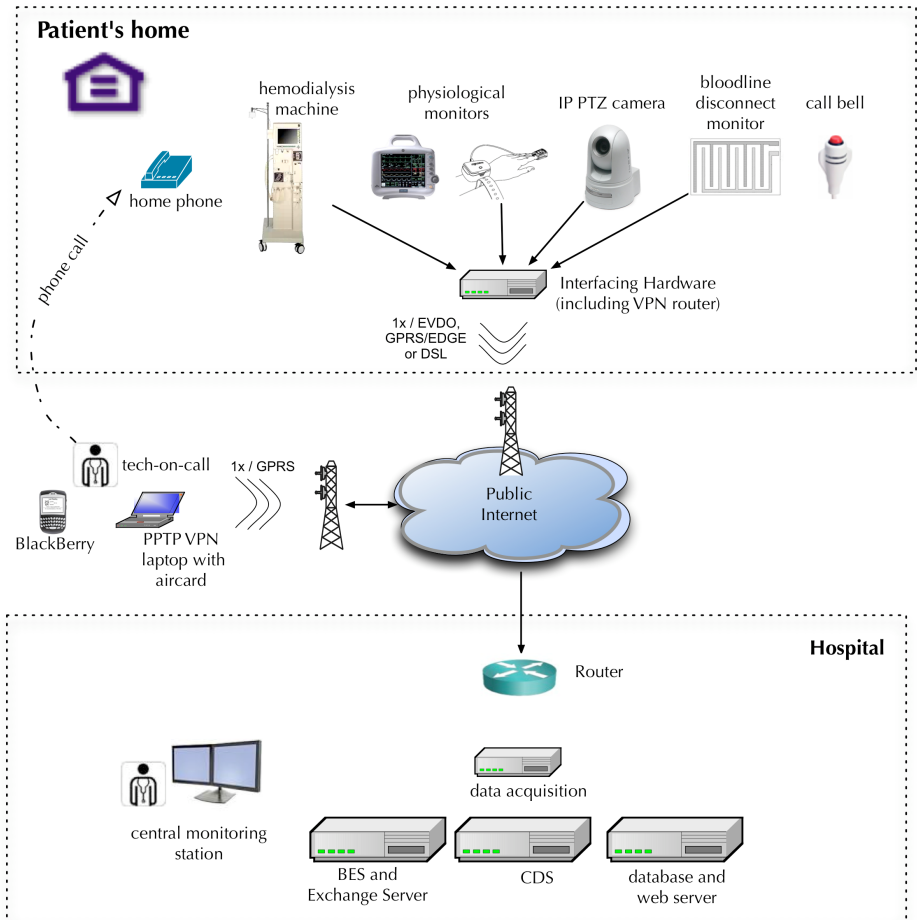


Fig. 1. Diagram of remote patient monitoring intervention for home hemodialysis. Data from the hemodialysis machine, physiological monitor, camera, bloodline monitor, and call bell are securely transmitted to the hospital systems. Data are continually monitored in real-time. Exceptions are routed to staff-on-call to address problems and emergency conditions.

patient's discretion. This was used as an aid in remotely troubleshooting the dialysis machine as well as had the ability to check on a patient during a serious alarm condition. 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 BlackBerry mobile device [10]. The alerts contain relevant information, current patient vital signs, and the patient's home phone number for quick access via the BlackBerry'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. (See figure 1)

3 Results

Patient Themes. The main themes from the patient interviews were as follows: *Security and comfort; Dependency; Adherence, Accountability and Privacy.*

Security and comfort. The intervention was found to be particularly supportive of family-caregivers and was viewed as a surrogate for nursing care. Patients remarked on how the system was used to check on details of their treatments, such as the amount of ultrafiltration being performed and their resulting weight and blood pressure. Nursing staff were able to react and advise adjustments to their prescription in a timelier manner. Patients also felt that there was some security and comfort knowing that they were being monitored and that the nursing staff would call when they noticed problems with their treatments. This notion of security and comfort extended to family members as well. The impact of home hemodialysis on family members is often severe and considered a barrier to adoption. The experiences of patients were that family members viewed the monitoring system positively.

Dependency. Though the system was proposed for only transitional use, there was an unwillingness to have it removed. Even those patients with an uneventful transition continued to insist on remaining on remote monitoring. Care providers should be aware that patients perceive remote monitoring as a safety feature and its removal can generate anxiety among patients who have developed an unexpected dependency.

For the most part, patients were uncomfortable or unwilling to part with the system after the study period was complete.

Adherence, Accountability, and Privacy. The monitoring system revealed that patient adherence is a significant issue amongst home hemodialysis patients. Patients failed to routinely perform blood pressure measurements prior to treatment, and on average dialyzed no more frequently than conventional patients, despite the clearly demonstrated health benefits of regular and more frequent therapy. This lack of adherence confirmed staff suspicions, as a result of reviewing poor monthly blood results. However, the use of the remote monitoring system provides direct documentation that the patient is not adhering.

Patients become aware of the level of accountability from the first phone call they receive from nursing staff. For most patients in this study, this access to detailed information of their treatments was not viewed as negatively as with others. Most felt that this was the system at work, ensuring their safety and helping facilitate their care.

These adherence problems raise the issue of accountability of the clinician to the patient as well. The presence of these new clinical data sets out a professional obligation for the clinician to act upon the data and help the patient through periods where they are having difficulty complying with the prescribed level of treatment. Thus, the notion of accountability is indeed shown to be bidirectional between patient and provider.

There was also concern over privacy and the “Big Brother” effect of using remote monitoring. Patients expressed concern over the detailed knowledge their caregivers would have of their schedule, frequency and habits when dialyzing at home. However, the loss of personal privacy through the use of remote monitoring is viewed as necessary for ensuring their safety. They do not distinguish between those aspects of the system that are related to safety and those that could be used to monitor adherence. There was even the view that the accountability was good for them and that it “put them on track” and “keeps you in line”.

Nursing Themes

The nurse’s diminishing role in direct care. The findings from the interviews indicated that the nurses were able to perform a more holistic form of nursing with NHD patients, since they were a dedicated resource to assigned patients. This nursing relationship could continue through the use of remote monitoring, and encompass the following aspects of nursing care: adherence to treatment and patient routine; adjustments to treatment; addressing technique and setup problems.

Monitoring-Mediated Nursing. These aspects of care are either more difficult to do without the use of remote monitoring or are less timely, due to the lack of information at the time the problems occurred. These aspects of care can be considered *monitoring-mediated nursing*, where the nurse continues to care for the patient through access to information that they would have otherwise obtained directly in a conventional setting. Some of the monitoring aspects of care that the nurses would do in conventional hemodialysis have been replaced through automation through the use of the rules engine of the system generating alerts.

4 Discussion

Analysis of the qualitative data indicated a unique relationship between nurse and patient, and their respective roles in providing care. To articulate this relationship, the Orem’s nursing theory may be applied. Healthy individuals normally have developed operative powers and capabilities to care for themselves, known as their *self-care agency*. When ill, an individual’s self-care agency may be diminished, and their care demands may increase significantly. This is especially true of hemodialysis patients, since the therapy to treat their condition is complex. Patients unable to meet the basic requirements to sustain their well-being will require dependent-care to meet their needs.

The imbalance between the therapeutic care demands and the patient’s ability to perform self-care is known as a *self-care deficit*. (See Figure 2). Orem’s self-care deficit theory is used to express the role of nursing in the context of addressing this

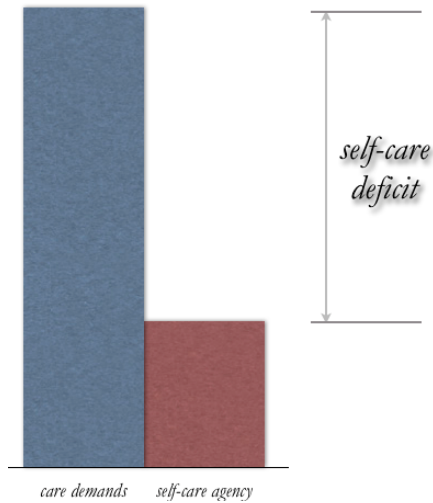


Fig. 2. Patient self-care deficit. Patients with complex chronic conditions typically have heightened care demands and have a reduced capacity to care for themselves, or reduced self-care agency. The unaddressed gap between these demands and agency is the self-care deficit. For conventional hemodialysis patients, this is normally addressed through nursing care.

self-care deficit. Central to the theory is that nurses assist those patients with a self-care deficit by enabling them to regain the requisites for self-care agency [11].

In the case of conventional hemodialysis, the bridging of this gap is never achieved through patient self-care agency alone. The deficit is addressed solely with nursing care. There is no expectation that the patient will ever address this deficit through self-care.

In contrast, the expectation of home hemodialysis patients is that they will address the deficit themselves. The home hemodialysis patients from this study felt ultimately that the responsibility of their care lies with them.

A portion of the deficit is addressed through training, which enhances their self-care agency. Added with the enhancement of patient's self-care agency is the continued nursing support that the patients receive on occasional homecare visits. As shown in this study's findings, nursing staff transition the patient onto the therapy from training by slowly lowering the "patient dependency" on their care. The dependence is never entirely eliminated but is far from the levels that conventional patients receive.

Finally, the results of this study suggest that this self-care deficit is bridged by the addition of *monitoring-mediated support*. This support replaces those nursing functions that were the norm in conventional hemodialysis. This includes the safety aspects of monitoring that have been automated through the rules engine component of the system, and the aspects related to adherence, adjustments to treatment parameters, and addressing technique issues.

This model can be shown to accommodate those patients that have significant dependent care through a family member. This added support may redistribute the care provision between the other components, but does not necessarily replace any

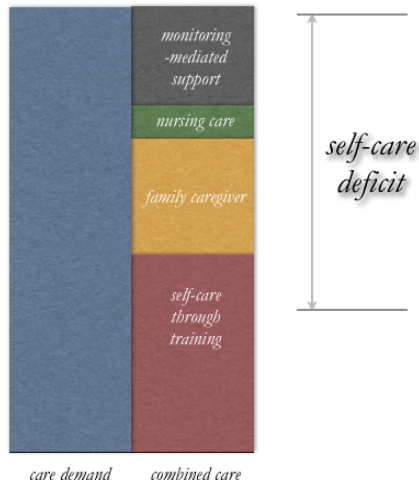


Fig. 3. The patient self-care deficit gap bridged. The component elements include enhanced self-care agency through training, family caregiver support, nursing visits, and monitoring-mediated support.

one component. The needs of family caregivers are often neglected in these cases, and support for them is required to help them cope with the patient care demands. The monitoring support has been shown here to be an effective means to complement this role and that of the nursing staff. (See figure 3)

5 Conclusion

With interventions such as monitoring-mediated support, patients with complex chronic conditions have the capacity of self-care with even the most difficult of hospital-at-home therapies. They now share the responsibility of disease management with their caregiver. With this empowerment comes the realization of a new level of accountability that patients have to their caregiver.

There were patients that expressed concern that their caregivers knew of their deviations from the prescribed frequency and duration of their home therapy, their lack of adherence, and their personal routine. For most, this was an acceptable risk to their personal privacy for ensuring their safety. Nevertheless, policy is needed to ensure that there is appropriate use of information by providers, given the unprecedented access the system allows. Self-care through remote monitoring shows great promise for empowering patients and leading to improved outcomes. This does not come without cost to the patient however, who now has greater personal responsibility and accountability for their health. Promising results from this study indicate that patients, for the most part, are willing to take on this cost in exchange for safety and improved outcomes.

The extension of Orem's self-care deficit theory demonstrated here attempts to explain the relationships and interaction between self-care, dependent-care, and a technological support intervention. There is significant interest in patient self-care in

healthcare currently, due to the positive outcomes and empowerment it can achieve and as a result of the challenges in meeting the care needs of a growing population of patients with chronic disease. Developments in monitoring-mediated support can be shown to assist in facilitating patient self-care with complex therapies.

Innovations such as home hemodialysis cannot reach their full potential if barriers to adoption to continue to exist. An intervention to facilitate the adoption of an innovation is often needed in many other areas of technology adoption. The use of remote monitoring is but one example of this bridging intervention to a therapy or system that will have a net benefit to patients with complex chronic conditions.

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