Telematics In The Neonatal ICU And Beyond: Improving Care For High-Risk Newborns And Their Families

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The Beth Israel-Deaconess has recently been awarded one of 19 contracts from the National Library of Medicine (NLM) to develop, implement and test a telemedicine application to support the care of Very Low Birth Weight Infants. This project is the only one to focus on the care of newborns. We believe that this project will provide a new national approach to managing the care of high-risk newborns by leveraging evolving communication technology.

INTRODUCTION

With the support of the National Library of Medicine's (NLM) Telemedicine Initiative, we are developing a telemedicine intervention that will provide enhanced educational, emotional, and medical support to families of high risk newborns both during their hospitalization and following discharge. We believe that the innovative use of this emerging technology will not only increase parental understanding, comfort and overall satisfaction with their baby's care in the Neonatal Intensive Care Unit (NICU), but will also improve the child's overall health status and clinician satisfaction. In addition, the improvements in family involvement, discharge planning, education, and follow-up enabled by this system may allow infants to transition home even earlier in their hospital stay and thereby provide a clear cost savings.

PROJECT OVERVIEW

The project is divided into a design phase, now complete, an implementation phase, and a deployment phase. We have conducted focus groups of past and current families of NICU babies to identify family needs that may be met by telematics technology, and have configured and tested a telemedicine home station. We are currently developing family education materials, configuring a high-bandwidth telecommunications network, collecting baseline evaluation data, and training providers in the operation of the project systems.

We plan in October, 1997 to start deployment of telemedicine workstations. Up to one hundred families of very low birth weight newborns (i.e., birth weight less than 1500 grams) will be recruited for an evaluation study that will run for 18 months. The project will end with a six month evaluation and reporting period.

RELEVANT CLINICAL ISSUES

Neonatal Intensive Care Units provide a wide array of diagnostic and therapeutic services to sick newborns. Each year over 200,000 infants require NICU care across the United States. More than 50,000 of these infants are born weighing less than 1500 grams. Significant technological advances have been made in the care of these very low birth weight (VLBW) infants over the past thirty years. Basic scientific and clinical investigations have led to a series of new therapies which have substantially decreased mortality within the NICU without increasing the burden of long-term morbidity for high risk newborns.[1]

Despite the successes of NICU technology, few other events are as emotionally overwhelming to a family as the admission of their newborn infant to a NICU. Many factors contribute to these feelings of anxiety including:

Multiple family members as patients

When a mother delivers a critically ill newborn, she must cope not only with her child's illness but also with her own recovery from the normal stresses of childbirth. Even after maternal recovery, families still may be faced with more than one patient to support because of multiple gestations.

Prolonged separation of parents and child

Several barriers may interfere with a family's ability to develop and nurture a relationship with their child as well as to gain the skills and knowledge necessary to become active participants in their child's care. Typically, the mother of a VLBW infant remains hospitalized for only a few days and then returns home while her baby remains hospitalized for several months. Since many families rely on two incomes and must juggle both the demands of work and care for other siblings, opportunities for contact with their hospitalized infant and his/her NICU providers may be limited.

Lack of familiarity with critical illness

For many families, their newborn's NICU admission is their first encounter with life-threatening illness. Parents are often over-whelmed by the unfamiliar and potentially frightening NICU environment. The pressures to absorb a tremendous amount of new medical information on a wide variety of topics related not only to the child's care in the hospital but also following discharge intensify these feelings.

A complex post-discharge system of care

Although the NICU staff is a main source of support during hospitalization, this relationship is abruptly changed at discharge. Rather than relying on these clinicians to provide continuous monitoring and care of the child, families must assume the role of primary provider. However, many families will have no previous newborn care experience, and few will have experience with a 4 pound infant. Parents may not remember how to perform even the simplest of procedures, and they may not have the sophistication and resources to identify and secure assistance. Questions and concerns about a baby's health may occur throughout the day and night. In the community, unlike the NICU, there may not be providers available 24 hours per day to personally evaluate and respond to these concerns.

ROLES FOR TELEMEDICINE

Defining clinical roles for telemedicine technologies has been an iterative process that has benefited from the input of experienced NICU clinicians, information technologists, and over 40 NICU families who have met in a series of structured focus groups. From these discussions several key interventions have been identified and relevant needs delineated:

Family paced learning

In the NICU, families must rapidly assimilate a wide range of unfamiliar knowledge, including clinical jargon and special care requirements. The computer can both reinforce new knowledge that clinicians are providing to families, and give families more information about events that can occur and how to deal with them.

We will provide instructional text and videos to parents about common clinical conditions that affect very low birthweight newborns, and about common baby care activities such as feeding an bathing. We will also provide a "kids corner" web site that contains suggestions for parents on activities for brothers and sisters of newborns, and information about the NICU designed to be read by children.

Emotional support

During a baby's NICU stay families often report feeling a "rollercoaster" of emotions, both highs and lows, along with uncertainty about what may happen next. Through videoconferencing and chat groups, telemedicine will be used to enhance the ability of families to interact with clinicians and with other NICU families to provide support.[2] We also believe that when families are unable to visit, the ability of families to see a video image of their baby will help relieve anxiety that parents may feel and will help families come closer together at a stressful time.

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Orientation to available services

Many services are available to NICU families, both within and outside the hospital, that families aren't always aware of. We will provide basic information through the web on cafeteria hours and menus, parking, and local restaurants, as well as on-line information and links to community service organizations, government agencies, and religious support services.

Discharge and follow-up care

We will provide individualized discharge information electronically to give families an easy way to access the information repeatedly if they have any questions after discharge, and to help assure that complete information is given to the families.

We also plan to provide electronic follow-up visits where clinicians knowledgeable in the care of high risk newborns will initiate videoconferences with the home in the days immediately following discharge. Families will also have the ability to contact the NICU electronically if they have concerns about post-discharge care, and clinicians will be able to see the baby using the video link.

IMPLEMENTATION

Enrollment

We intend to introduce the family to the telemedicine system at approximately three days following delivery of a very low birth weight baby. The three days will give the family an opportunity to begin to work through the emotional and practical issues involved with a VLBW baby, and to become familiar with the NICU environment and staff. After this period, NICU clinical staff will explain the system to the family and ask the family if they are willing to participate in the project.

Project participants will be selected from very low birth weight infants born at Beth Israel and cared for in the NICU. We intend to require as few criteria as possible for inclusion in the study so that the trial results will reflect the diversity of family backgrounds found in the NICU. For example, lack of telephone service in the family residence will not be used as an exclusion criteria. In such cases, basic telephone service will be arranged for the duration of the study period.

We plan to involve 30 to 50 babies in the project with an equal number in a control group. Babies will be followed for 3 to 6 months following discharge from the hospital to allow the study to include the psychosocial and family support aspects of bringing home and raising a VLBW baby. Each baby will therefore participate in the project for approximately 6 to 9 months.

Technical architecture

We are planning a combination of technologies to deliver telemedicine to the home. Fixed educational content and other materials that are not subject to frequent changes will be delivered by CD-ROM or through files loaded on the home station hard drive prior to installation. Current data on the baby's condition will be provided over the Internet using Microsoft Active Server Page technology accessing a server-side patient data base.

The home station hardware is currently implemented as a full-tower 200 MHz Pentium Pro processor computer with 326MB of RAM, a 3.1 GB hard disk, a 8x CD-ROM drive, a 33.6 full duplex fax modem with a speakerphone, a SoundBlaster 16-bit sound card speakers, a 17 inch SVGA color monitor and a 3.5" floppy disk drive. In addition, it is equipped with a PictureTel Live 200 camera and videoconferencing board, and an ISDN with NT-1 box. A two-channel 128 kbps BRI ISDN line provides videoconferencing capability.

Web page design

A secure web site will be created for each baby. The site will include recent photographs, clinical measurements such as the baby's weight, length, as well as the most recent feeding plan, progress notes, and the names of clinicians on the care team. Dynamic links to the NICU's Hewlett-Packard CareVue charting system will provide much of the clinical information. Other information will be captured from administrative databases or from direct clinician entry.

Data will be provided in a multimedia format. In addition to the most recent still photograph, there will be links to a gallery of earlier pictures and video clips. Project staff and volunteers will take still pictures of each baby during relatively quiet periods in the NICU for updating the baby's web site.

Clinicians will be able to make voice, text, and video annotations to the baby's page, both to describe the baby's progress and to communicate messages to the family. Trends of the baby's height and weight will be shown as a graph generated from a clinical data base.

Security and confidentiality

Security and confidentiality requirements have several facets: providing secure communication between the home and the hospital, assuring confidentiality of information at the NICU, assuring confidentiality at the home (e.g., from other family members), and assuring privacy in audio and video communications.

We plan to use a secure sockets layer to assure security of communication to the browser. We are testing a second layer of content encryption to assure that data is accessed only by authorized users. We will provide a hardware token to identify each family member and each healthcare provider who will have authorized access to patient records.[3,4] Users will be required to enter a valid name, PIN, and the correct number displayed on the hardware token to gain access to the system.

We will provide cameras on wheeled carts that can be moved to the baby's bedside for video conferencing. The broadcast nature of video makes placement of monitors in the NICU a particular concern. Audio presents additional challenges, since while it's possible to shield video by appropriate placement of monitors or with physical screens, sounds transmit through an open area like the NICU with ease.

We will be providing an appropriately private area for physicians and families to hold videoconferences and are investigating a variety of approaches for assuring confidential transmissions in the NICU. Having a staff member present during a video-assisted family visit will help in handling unusual events that occur often in the NICU, such as an alarm going off for a baby nearby. We are developing workflow procedures to manage these clinical issues and to respond to confidentiality and privacy concerns of families and clinicians.

EVALUATION

The evaluation of telemedicine's impact will focus on two primary outcomes. First, we will analyze differences between the intervention and control groups in the quality of NICU care as judged from the family's perspective. Second, we will examine the effect of telemedicine on healthcare resource utilization both within the NICU and following discharge.

The Picker Institute is developing a standardized family survey instrument from the focus groups and structured interviews with families of NICU babies. The Picker Institute has done extensive research to develop measures of quality of care in hospitals and in a variety of ambulatory settings. These measures, generated from structured analysis of patients' and their families' perspectives, have been demonstrated to be valid[5] and to provide a valuable adjunct to the usual provider-focused indicators of medical care quality. The NICU specific instrument will include dimensions with direct relevance to telemedicine's assessment, such as the quality of information and education provided, the degree to which care was coordinated, the extent of emotional support available as well as measures of the continuity of care during periods of transition (e.g. at the time of discharge, or at changes in NICU personnel).

To assess the economic impact of telemedicine, total hospital charges and costs will be obtained from the hospital's fiscal information system. Physician charges will be obtained separately. We will also use an existing instrument[6] which assesses multiple aspects of infant health including 1) post-discharge health care resource utilization including hospitalizations, emergency room and doctor's visits, medication/medical supply use and preventative service use, 2) presence of co-morbidities and 3) measures of parental perception of the child's health and developmental achievement.

SUMMARY

We believe this project will provide a new national approach to managing the care of high-risk newborns. The linkage of home, clinician, and tertiary hospital will allow high risk newborns and their families to benefit from a more highly coordinated system of care where all parties are able to easily share and benefit from information relevant to the care of the child.

ACKNOWLEDGEMENTS

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