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Baby CareLink: Collaborative Tools to Support Families*

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Application of information and communication technologies designed to enhance decision making and communication between providers, patients, and their families will play an important role in supporting the relationship between patient and provider and will assist patients to better understand their illness experience and how their own values affect decision making [1–8]. We call this tight integration of software and people in health care Collaborative Healthware [9–11]. Baby CareLink, an application of Collaborative Healthware, links NICU staff with families of medically complex newborns [12]. Using a Web browser, parents can receive daily updates and track information about their baby's health, see recent pictures of their baby, communicate with NICU staff, access a personalized knowledge base for newborn care, and provide feedback regarding the care process. Following discharge, Baby CareLink can be used to support care coordination, follow-up monitoring, and ongoing communication with parents. Baby CareLink is Collaborative Healthware that supports the relationship between parents and healthcare provider by engaging the family as full partners in the healthcare process.

The birth of a child is a great joy for most families, but for families whose children require care in the Neonatal Intensive Care Unit (NICU) it is a time of great emotional distress. The care of premature infants is truly a miracle of modern medicine. Incubators for premature infants were developed in the 1930s and supported a controlled environment for the infant. For the most part, the prematurity of the lung was the limiting factor to survivability of the infant. Surfactant is a naturally occurring substance produced by the lung to decrease the surface tension in these small air sacks. Only more mature lungs produce this substance. Even modern ventilators with small rapid tidal volumes had problems expanding the small air exchanging units in the lung called alveoli until the 1970s when surfactant was introduced. As doctors attempted to resuscitate smaller and smaller infants, their success rate improved. Concomitant with the introduction of improved ventilation technology was a dramatic improvement in fertility technologies. Pharmaceuticals were developed to help stimulate ovulation and support tenuous pregnancies. Women were also able to receive already fertilized eggs to overcome biological barriers to conception. The result of these advances has been that preterm birth rate has increased 9% since 1990 and 23% since 1981.

Success, however miraculous, comes at a great cost. Neonatal care accounts for more than 1% of total US health expenditure. More than $18 billion is spent in the United States each year on the care of premature infants; accounting for 25% of total annual expenditures on child and maternal health. The average cost for the birth of a low birth-weight (less than 2500 g) baby is $50,000. Premature twins would cost $100,000. More-over, costs post-discharge for these infants during the first 12 months are 10 to 30 times higher than for healthy, full-term babies.

Today children smaller than 500 g (approx 1 lbs) are cared for in the NICU and have excellent prospects of growing up to be normal adults. About 5% of these small infants die and another 10% have serious disability. The emotional costs for the parents, although hard to quantify, are profound. Parents hope for and expect to bring home a healthy baby. Many parents in their teens, 20s, 30s, and even 40s have had little previ-ous contact with the health system, much less with the type of high-tech medicine they encounter in the NICU. A variety of emotions frequently overwhelms the new parent of a premature infant in the NICU, the central concern, of course, being whether the child will live or die. Parents often describe the experience as an "emotional roller coaster." Families are faced with logistical issues as well. If there are other young chil-dren at home, who will care for them when the parents want to be in the NICU with their baby? If a parent has maternity or paternity leave from work, does he or she use this time while his or her baby is in the NICU or several months later when the child can come home? During the prolonged hospitalization parents must assimilate a large body of knowledge relevant to their baby's care. This includes not only information about routine baby care, but also the special needs of their high-risk infant. Their learn-ing is often impeded by fear and anxiety and parents become overwhelmed with infor-mation and advice from multiple sources. A study by Brazy [13] showed that during the first week of their baby's life, more than half of parents spend at least 20 hours seeking information. Even after 4 weeks of hospitalization, more than one third of parents perform the equivalent of a half-time job seeking information about and for their child. In addition, and perhaps more alarming to parents, the need for informa-tion and problems with its access do not end when the baby goes home. Skills and knowledge gained at one point may be lost or forgotten in the whirlwind that can exist during the early days following discharge. Almost 40% of babies discharged from the NICU return to an emergency room, and half these visits are generally recognized as medically unnecessary. Like most areas of health care, NICU care has great local and regional variation. Although the average stay for a preterm infant is about 3 weeks, gestational age or birthweight are among the best determinate of length of stay for any particular infant. First, the child has to be medically ready. Most infants progress from an early intensive care phase to the feeding and growing stage. Once in this second phase, it is only a matter of time until parents can take their child home. Clearly the infant needs to meet some medical criteria before going home, but the judgment of the clinicians about the parents' and community's readiness is the second factor deter-mining the date of discharge.

Baby CareLink History

Baby CareLink was developed at Boston's Beth Israel Hospital as part of a federal initiative to evaluate telemedicine's impact on clinical care. Starting in 1997, a team of neonatologists led by Jim Gray and neonatal nurse specialists led by Grace Pompilio worked with the teams of informaticians at the Center for Clinical

Computing to develop an Internet-based application to support families with infants in NICUs.

Six major areas of clinical content and resources were part of the original Baby CareLink including a daily clinical report, a message center, a see your baby section, a family room, a clinical information section, and a section focused on preparation for discharge to home. The daily report is webpage that provides clinical updates about a baby's clinical care and status. The message center is a secure WWW-based messaging system through which parents can share confidential communications with members of the NICU staff. Baby CareLink also contains a context-sensitive messaging throughout the CareLink site to allow parents to easily compose messages related to the content they are viewing. The see your baby section is a pictorial daily journal comprised of images captured by the staff with a consumer grade digital camera. Baby CareLink also provides a mechanism for allowing families to share these photos outside of the confines of the CareLink security architecture. By changing a picture's status through the WWW-based interface, parents can post pictures to a password protected WWW where their families and friends can see their baby. The family room provides a potpourri of supports including answers to common questions, information about services available to families, links to WWW-based resources, and an online library for browsing available print and video resources. "The Kid's Corner" provides a collection of information and support materials specifically geared for older siblings of our patients. "The Emotional Side of the NICU" allows parents to both read about the issues that confront families of high-risk newborns and view high-quality digital video of NICU families discussing how they coped with their NICU experience. The clinical information and care section describes the issues present at various stages in a baby's NICU stay including when a baby is first admitted, as a baby stabilizes and family members becomes more active participants in their baby's care, and the period prior to discharge when families prepare to take over all of their baby's care at home. The "NICU-Pedia" provides an online encyclopedia of clinical conditions, tests, treatments, and medications relevant to the care of high-risk newborns. The preparing for discharge section is an on-line discharge teaching module where parents can view multimedia modules describing the knowledge and competencies they must acquire prior to discharge. This module is constructed so that NICU clinicians can individualize the content for each baby's needs using a simple WWW interface. It also allows parents and clinicians to track acquisition of knowledge.

A randomized controlled clinical trial of this early Baby CareLink was conducted between November 1, 1997 and March 30, 1999 and published in the journal *Pediatrics* [12]. This study showed Baby CareLink significantly improved family satisfaction with inpatient care and definitively lowers costs associated with hospital to hospital transfer. The study suggested the use of Baby CareLink supported the educational and emotional needs of families and facilitated earlier discharge to home.

In July 1999, a commercial version of Baby CareLink was developed for national use by Clinician Support Technology (CST). CST's early version of Baby CareLink did not support two-way videoconferencing.

Baby CareLink Today

CST Baby CareLink provides parents, clinicians, and care managers with innovative Internet-supported tools that foster an environment where parents become more active and empowered in their baby's care. Providing parents with timely information estab-

lishes a common framework for understanding developmental milestones and reinforces discharge education. All content in CST Baby CareLink is written in easy to understand English and Spanish. CST incorporates multimedia, voice-over and Web technologies to make complicated information more understandable for all parents, even those with low reading, computer, or health literacy.

CST Baby CareLink helps grow a better parent: one who is more comfortable, confident, and competent in caring for their fragile newborn. These parents are more likely to take their infants home sooner and less likely to utilize valuable emergency room resources for routine care issues. From anywhere, using an Internet browser, parents can access an individualized knowledge base for newborn care, receive daily updates, and track information about their baby's health and progress. Parents can communicate with the NICU team through a secure messaging center and receive prescribed educational modules.

Baby CareLink offer a comprehensive, organized platform for families to document issues for discussion with their primary physician, track their infant's progress toward developmental milestones, and maintain accurate, up-to-date immunization records. Parents can access a knowledge base particular to infants who experienced a NICU stay and who may have ongoing medical problems and/or an anticipated developmental timeline that differs from that expected with a full-term healthy infant. Early recognition by parents of a delay in reaching critical milestones helps ensure that an infant's potential is maximized. In addition, parents are provided with the early warning signs that could indicate if their baby may need to be seen by a physician. This helps parents identify potentially serious clinical problems before they progress and lead to emergency care and/or re-hospitalization. This information can be delivered at predetermined intervals such as during flu and allergy seasons to serve as a reminder. Collaborative Healthware applications can make the challenges associated with taking a baby home from the NICU a bit easier for parents and for the clinicians who care for them.

CST Baby CareLink has evolved to a solution for broader aspects of maternal–child care to support the family from the beginning pregnancy though the first year of life. Baby CareLink has content and tools for parents, tools for clinicians, and tools for care managers.

Content and Tools for Parents

The content for parents starts with pregnancy and supports the parents' educational and emotional needs though their child's first year of life. Topics might include fitness and lifestyle, nutrition, growth and nutrition, infant safety, and immunization. For the medically complex infant requiring care in the NICU, Baby CareLink currently has the following modules:

1. **Clinical Dashboard** is the opening portal to all the functions of Baby CareLink. From this page a parent can easily see if there are messages, a new educational prescription, or a clinical update concerning their child's health.
2. **Welcome to the NICU** is a description of the NICU setting, visiting policies, hospital information, and important phone numbers.
3. **The Meet the Staff** page allows parents to see a photo and identify members of the NICU team.
4. **The See Your Baby** page is a secure, patient-specific photo gallery that can be easily updated by the NICU team.

5. **The Message Center** is a secure messaging center, linking individual families to their baby's entire care team.
6. **Clinical Information** is a complete NICU reference library, including an encyclopedia and glossary.
7. **Caring for Your Baby** is a comprehensive parent guide to baby care, safety, and development.
8. **The Family Room** is a comprehensive resource center with information on books, emotional issues associated with the NICU experience, Web links, and sibling games.
9. **Preparing for Discharge** provides individualized discharge teaching tools for parents. Parents can submit questions online and clinicians can monitor progress and keep a record of completion.
10. **My Journal** allows parents to keep track of questions they may have about Baby CareLink educational materials, take notes on material relevant to their baby, and/or to bookmark selected Web pages for future reading.

More than 1500 topics are covered and are written in English and Spanish at a sixth-grade reading level. To accommodate different learning styles, the content is delivered in multimedia using text-to-voice and video clips.

Tools for Clinicians

Clinicians can prescribe and track educational modules for parents, are supported by rule-based care, and discharge planning forms and documentation. Like parents, clinicians use the message center to communicate with families.

Tools for Care Managers

Care managers have tools that help in the transition home, provide for ongoing assessments, and have access to the same message center as do the clinicians and parents, thereby fostering collaboration.

The Digital Divide

Unfortunately, there has always been a gap between those people and communities who have access to the newest technology available and those who do not. The term "digital divide" is used to refer to this gap. While there are conflicting reports on the extent of the divide most agree that a divide does exist. *A Nation Online: How Americans Are Expanding Their Use of the Internet* [14] reports on the rapidly growing use of new information technologies such as the Internet across all demographic groups and geographic regions.

More than half of the nation (54%) is now online and the rate of growth of Internet use in the United States is currently two million new Internet users per month. The profile of computer and Internet users demonstrates that the rise in computer and Internet use is spread across a wide range of the population. Internet use is increasing for people regardless of income, education, age, race, ethnicity, or gender [14].

While Internet use continues to rise among people who live in lower income households, family income remains the main indicator of whether a person is likely to use a

computer or the Internet. Individuals who live in high-income households are more likely to be computer and Internet users than those who live in low-income households [14]. Internet use has also increased across all races and groups. White Americans continue to be the largest segment of the population using computers despite the fact that growth in Internet use rates was faster for blacks and Hispanics. Between August 2000 and September 2001, Internet use among blacks and Hispanics increased at annual rates of 33% and 30%, respectively. Whites, Asian Americans, and Pacific Islanders experienced annual growth rates of approximately 20% during these same periods [14].

For families who depend on Medicaid support, the emotional, social, and economic toll of serious illness is magnified not only by circumstance, but also by stereotyped preconception. For instance, Medicaid mothers who have preterm infants in Neonatal ICUs (NICU) are younger, have attained lower levels of education, may have had less prenatal care, and have more children at home than do mothers who have paid for in vitro fertilization. However, the circumstance of being poor and receiving support from Medicaid does not imply that a parent lacks the motivation or intelligence to use e-Health applications. On the contrary, a mother of a sick child is a powerful advocate for her child's health regardless of socioeconomic status. Collaborative Healthware can be a valuable and effective approach for this medically underserved and disadvantaged population that makes up such a large proportion of those families with low birthweight or medically complex newborns requiring NICU care.

Many medically fragile infants have complex chronic medical problems that place them at higher risk for postdischarge mortality, childhood morbidity from acute and chronic illnesses, and long-term developmental/educational difficulties. Those infants who are born into socioeconomically disadvantaged families are faced with even greater risk because they lack the financial resources and adequate social and emotional support they need. Providing Medicaid parents with the resources of Collaborative Healthware will enhance the early identification of critical issues facing families prior to and on integration into the community with a medically complex infant.

Despite the fact that compliance with postdischarge programs may help prevent adverse outcomes for their infant, many Medicaid families have a hard time following up with recommended medical care and developmental services. Collaborative Healthware applications can be used to support care coordination, follow up monitoring, and facilitate ongoing communication with parents and care partners. Early identification of issues facing families on integration into the community avoids costly readmissions and helps to decrease the stress associated with caring for a premature or lowbirthweight newborn.

Use of Baby CareLink

As of the beginning of 2004, Baby CareLink operates in 13 hospitals in 8 different states. In three of these states, Baby CareLink is being deployed as part of a State-Medicaid initiative. More than 4000 infants were registered in the system in 2003. These parents are logging onto Baby CareLink more than 6000 times per month and viewing more than 30,000 Baby CareLink Web pages each month.

Thirty-eight percent of the time parents access the educational material such as "caring for you baby" or "preparing for discharge." Thirty-four percent of the time, parents look at pictures of their infants. Twenty-eight percent of the time parents use the collaborative tools to receive personalized information from the clinical staff or to send messages back to the clinicians.

Case Reports

One infant was diagnosed with gastroschisis. The infant was delivered prematurely and scheduled for a secondary repair at the nearby Children's Hospital a few weeks after birth. The parents were bilingual, although Spanish was their spoken language at home. The parents were lent a laptop computer through the lending program so they could have access to Baby CareLink. They expressed the value of looking up information in Spanish so that they could better understand it. They were able to complete several of the discharge learning modules from home, and their baby went home a few weeks after his repair.

Premature babies are in the hospital for so long their parents cannot always remain in the area for their entire length of stay. Some parents opt to return to work while their baby is hospitalized and take their maternity leave once their baby comes home. One family from Wyoming was unsure of how they would care for their baby, and felt guilty that they couldn't remain in Denver to be with their baby. Both parents had access to a computer at work, and used the message center to communicate with the NICU team. The NICU team was able to provide updates on their baby's condition and assign discharge learning materials to the parents. The parents felt like they were doing something for their baby and were preparing for their infant's homecoming. This boosted the parents' confidence. The parents reviewed the educational materials and asked questions through the message center showing the NICU team that they had really read and thought about the materials.

For one infant with an extended hospitalization because of extreme prematurity, the mother visited almost every day. While in the NICU, she logged on to the site and read everything available. She entered chat rooms with other NICU parents, asking for suggestions about helping her baby to learn to bottle-feed. It was uplifting to see her find other resources outside of the NICU that she could use in supporting her baby's care. She utilized this resource effectively, giving the additional information to her baby's care team. Her baby's course was uncomplicated and the baby went home as soon as possible with a very confident young mother.

Discussion

Baby CareLink represents a new class of tools and applications in health care that we have termed "Collaborative Healthware." These tools enable patients and their families to be full participants in the care process. The introduction of programs such as Baby CareLink has the potential to change clinical processes. Parental discharge teaching, which was previously concentrated on the day of discharge, is now initiated earlier and provided over a more extended period of time using Baby CareLink. Parents are more motivated to learn and prefer the autonomy and ability to control the pace of their learning using the computer system on their own. Clinicians review with the parents any questions they have after reading the assigned Baby CareLink learning modules and assess their comprehension of the material. As a result of the targeted, personalized education, parents ask more informed questions and understand their challenges much better. Clinicians believe that parents who use Baby CareLink are more confident about caring for their children and are prepared to take the infants home sooner.

Clinicians adopt programs such as Baby CareLink in different ways. Some sites have not enabled parent-to-parent chat, and one site does not allow parent to clinician email.

On the other hand, several sites use Baby CareLink as their principal method to provide and document discharge education and learning. Baby CareLink has been used in teaching hospitals, rural hospitals, and inner-city hospitals. In each environment, parents from all socioeconomic backgrounds and prior Internet experience have embraced tools designed to help them help their infants.

The evaluation of clinical systems such as Baby CareLink represents a continuing challenge. The initial evaluation of Baby CareLink [12] involved a randomized clinical trial. Such an evaluation is complex, difficult, and expensive. Moreover, really clinical systems such as Baby CareLink are constantly changing and improving based on customer suggestions and good suggestions from a clinical advisory board. The underlying technology of Baby CareLink tries to provide "just-in-time" information to the parent. Providing the right information at the right time might change a child's care, but measuring this impact is quite difficult. Baby CareLink has delivered more than one-quarter million pictures of premature infants to their families while only 80,000 pages of discharge learning material. Does this mean that the pictures are more valuable than the educational material? Ultimately, each component of Baby CareLink provides part of a framework that allows patients and their families to better collaborate with their care teams. For some, this strengthens existing relationships and for others technology facilitates new linkages.

Collaborative Healthware supports the relationship between healthcare provider and patient by engaging the patient and their families as full partners in the healthcare process. In a collaborative partnership, patients expect that their clinicians will provide information and guidance. Patients expect that their clinicians will educate them and their families on illnesses, available therapies, potential outcomes, and complications, so that decisions can be made based on the patient's individual preferences [2,15–17].

More often patients are presented with opportunities to actively participate in decisions that affect their lives and well being [3,6,8,18]. While patient preferences for participation in clinical decisions vary greatly [1,2,4], the desire for information about their health and health care is high [19]. Patients want information that addresses their individual concerns and conditions as well as interactive tools to manage their health and disease [20,21]. Providing patients with enhanced health related information favorably affects their trust in, relationship with, and confidence in their healthcare providers [22].

Collaborative Healthware solutions allow the development of prescribed healthcare communities that facilitate effective connectivity among participants. These solutions provide better access to information for patients, better distribution of expertise throughout the healthcare system, improved collaboration and coordination of care, and improved quality of care. The enabling technologies of Collaborative Healthware solutions are based on secure sharing of information and knowledge in a cost-effective manner.

Technology can play an important role in restoring relationships between patients and the healthcare system. Technology can facilitate improvement in quality, cost, and patient satisfaction. Properly applied Internet technology can be used successfully as a platform on which to deliver interventions to patients that significantly enhance the outcomes of care [23].

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