



ELSEVIER

International Journal of Medical Informatics 69 (2003) 185–190

International Journal of  
**Medical  
Informatics**

www.elsevier.com/locate/ijmedinf

# The collaborative edge: patient empowerment for vulnerable populations

Charles Safran\*

*Clinician Support Technology, Newton, MA, USA  
Harvard Medical School, Boston, MA, USA*

---

## Abstract

*Objective:* The problems with access to care and the special needs for educational outreach for disadvantage or vulnerable populations of patients require innovation. This paper describes Baby CareLink use of information technology to support communication, consultation, and collaboration among colleagues as well as with patients, their families, and community resources. *Methods:* In response to the educational, emotional and communication needs of parents of premature infants and the clinicians who care for the infants and support the families, we developed Baby CareLink, a secure collaborative environment. Baby CareLink provides a nurturing environment where parents, even though remote from the Neonatal Intensive Care Unit, can actively participate in decisions surrounding their baby's care. *Results:* In a southeastern hospital serving a mostly Medicaid population in a rural setting, more than 300 parents have used Baby CareLink more than 11 000 times during the past year. Despite the common wisdom that Medicaid families do not have access to the Internet, approximately 85% of the parents access Baby CareLink from home, at work, from the library or other public access point. The median use of Baby CareLinks from outside the hospital by parents is 17 separate sessions. In a city hospital in the midwestern US which exclusively serves a Medicaid population, experience has been equally encouraging. More than 70 parents have initiated more than 600 secure sessions with Baby CareLink. In contrast to the rural hospital, only 35% of sessions have been initiated outside the hospital. *Discussion:* Experience with Baby CareLink suggests that families from all walks of life will use and benefit from collaborative tools that keep them informed and involved in the care of their children. The most significant barrier to wider deployment is bandwidth limitations into the homes of most families. The care of premature infants is a great example of an area where medical knowledge and ability has grown dramatically, and where information and communication technology holds enormous potential.

© 2002 Elsevier Science Ireland Ltd. All rights reserved.

*Keywords:* Baby CareLink; Healthcare; Internet; Patient participation; Medicaid; Collaborative healthware

---

\* Address: International Journal of Medical Informatics, One Wells Avenue Suite 201, Newton, MA 02459, USA. Tel.: +1-617-614-2600x123; fax: +1-617-614-2525

*E-mail address:* [csafran@cstlink.com](mailto:csafran@cstlink.com) (C. Safran).

## 1. Introduction

The past three decades have seen revolutionary changes in healthcare but only evolutionary changes in healthcare information systems. This must change if we are to realize the full potential of collaborative care and shared decision-making. Providers, patients and their families, and even payers must leverage the power of information technology to improve clinical care as well as satisfaction with that care, and to reduce costs. Counter-intuitively, perhaps the greatest potential benefit from increased use of information technology in healthcare would be realized by underserved and disadvantaged populations, who are not as disenfranchised by the ‘digital divide’ as is commonly thought [1].

The explosion of scientific knowledge in healthcare during the past three decades has been staggering, particularly concerning the basic understanding of pathophysiological processes at the genomic and proteomic level. This new knowledge has led to the subsequent development of therapeutics and biologicals to alter these processes. The application of micro-technology to modern healthcare has been nothing less than a miracle of modern medicine.

The progress with health information systems during the past three decades has been less impressive. While there has been a technological revolution in our societies thanks to the personal computer, wireless communication, increasing bandwidth, fast and cheap storage media, and the World Wide Web, the widespread adoption of information and communication technologies in healthcare is occurring more slowly.

Much has been written about why the diffusion of information technology has been slower in healthcare than in other industries and previous working conferences on hospital and health information systems have docu-

mented many barriers. While it is true that healthcare is not banking, insurance, or manufacturing, we do have something to learn from the marketplace.

Much of the immediate success of information technology in the financial sector has been due to its ability to replace repetitive tasks. As a result we all experience a different level of customer service not only at the ATM but in many routine interactions with business. In a recent article in *Information Week* 25 companies were highlighted as ‘innovators in collaboration’ [2]. Only 1 of these companies was involved in healthcare.

The article suggests that: ‘The next stage of collaborative business (for healthcare) is where cooperation among customers (individuals, families, and communities), suppliers (pharmaceutical, device manufacturers and medical supply companies), partners (national health systems, insurance companies and payers), and colleagues (physicians, nurses, other care providers, and support personnel) lets companies (health systems) do business in different and better ways.’ Since effective healthcare requires communication, consultation, and collaboration among colleagues as well as with patients, their families, and community resources, should not healthcare information systems facilitate these basic tasks?

## 2. NICU stresses family, inhibits communication

The care of premature infants is a great example of an area where medical knowledge and ability has grown dramatically, and where information and communication technology holds enormous potential [3,4]. Medical success [5] has increased the challenge for families [6].

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. Even modern ventilators with small rapid tidal volumes had problems expanding the small air exchanging units in the lung called aveolae until the 1970s when surfactant was introduced. Surfactant is a naturally occurring substance produced by the lung to decrease the surface tension in these small air sacks. Only mature babies produce this substance.

Concomitant with the introduction of improved ventilation 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 pre-term birth rate has increased 9% since 1990 and 23% since 1981 [7].

The smaller infants lack the ability to control their body temperature, breast or bottle feed, or sometimes breath without machine support. These infants require the support of highly specialized doctors and nurses and the Neonatal Intensive Care Unit (NICU). 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 [5].

NICU is truly a miracle of modern medicine, but it comes at a cost, both a dollar cost and an emotional cost for families who experience prolonged and unexpected critical care needed for their children. In the US the monetary costs of NICU and care for the first year of life of these infants exceeds 1% of the annual healthcare expenditure [8].

The emotional costs, while hard to quantify, are profound as well. Parents hope for and expect to bring home a healthy baby.

Many parents in their teens, twenties, thirties and even forties have had little previous 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 rollercoaster.’

In addition families are faced with logistical issues as well. If there are other young children 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, do they use this time while their 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 learning is often impeded by fear and anxiety and they become overwhelmed with information and advice from multiple sources.

A study by Brazy showed that during the first week of their baby’s life, more than half of parents spend at least 20 h seeking information [6]. 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 information 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 within 30 days to an emergency room, and half these

visits are generally recognized as medically unnecessary.

### **3. Communication technology linked to higher family satisfaction**

In response to the educational, emotional and communication needs of parents of premature infants and the clinicians who care for the infants and support the families, we developed Baby CareLink, a secure collaborative environment. Baby CareLink was originally funded by the National Library of Medicine [9] and is now commercially supported by Clinician Support Technology (Newton, MA).

Baby CareLink provides a nurturing environment where parents, even though remote from the NICU, can actively participate in decisions surrounding their baby's care. The improved communication and customized education gives parents more confidence about overall care of the premature infant. As communication between parents and clinicians improves, quality of care also improves dramatically.

With Baby CareLink, parents monitor their babies from home, schedule visits and find medical information about their child's condition. From home, parents monitor their babies at any time, and check on the latest available information updates via Daily Reports, Doctor's Notes and a Baby Growth Chart. Perhaps more important, from the privacy of home at any time of day or night, a parent can research some 700 newborn-related subject areas stored in a massive database containing clinical content and resources such as baby care and safety reference material.

Early every morning, parents log onto Baby CareLink to see an updated daily clinical report. Often they will find a message from

the night shift nurse. Sometimes, the nurse suggests a topic for parents to review like 'giving your child a bath.' With the click of a mouse, the parent is directed to a topic related to their child's care. At the very least, every morning a new digital picture may be posted on the secure website dedicated to each child.

Baby CareLink also provides information to expedite and streamline the hospital discharge process. By the end of 2 months parents are more comfortable, confident and competent to take their small children home knowing that they are still connected to the NICU doctors and nurses. Baby CareLink helps parents through a time of crisis and provides continued support throughout the first year of life.

The results of a randomized study of Baby CareLink showed a 75% reduction in reports of quality-of-care problems. The number of respondents answering positively to the question, 'Was there a problem with your child's care?' was cut from 13 to 3% for respondents using Baby CareLink. Moreover, parents reported better communication, higher levels of satisfaction with care and tended to take their children home earlier.

This study, with only 58 families, suggests an unmet need with substantial clinical benefits if such collaborative technology could be widely deployed. The results suggest that families in crisis would embrace Internet-based tools and services regardless of their prior use of computers or the Internet, their socio-economic status, or their educational level, providing they can read English.

### **4. Bridging the digital divide**

Many believe that families who live on the far side of the so-called 'digital divide' have other pressing health and social problems that need to be addressed before providing them

with Internet access and tools. In fact, physicians and politicians have reportedly suggested that families should be given taxi vouchers instead of Internet tools if access to healthcare and information is the problem. They have also suggested that parents should be provided brochures and books on the subject because they are free or relatively low cost.

These views reinforce stereotypes and ignore the fact that traditional approaches to healthcare for disadvantaged populations contributes to the ‘healthcare divide’ in our country. Morbidity and mortality rates for infants and children of Hispanic and African Americans is significantly higher than for white Americans and this gap is growing [7,10]. The problems with access to care and the special needs for educational outreach require innovation. Recent data from the Pew Internet and American Life Project suggest that access to the Internet by Hispanic Americans increased 19% in the past year; faster than any other population segment (<http://www.pewinternet.org>).

Experience shows, however, that the most significant barrier to wider deployment is bandwidth limitations into the homes of most families. During the first 2 years of operation of Baby CareLink, getting broadband into the home required two-business-weeks to install and was not possible in some locations [9]. Commercial support for Baby CareLink required adapting the technology to available bandwidth. Moreover, about 40% of families of low birthweight infants live in inner cities and/or are on Medicaid, the federally funded and state administered health payment system in the US. A second barrier to wide deployment is that a large proportion of this population speaks languages other than English, such as Spanish.

With these known barriers in mind, Baby CareLink was redesigned to support broad

populations of patients, including those who are considered disadvantaged. Based upon the work of Brennan [11], Gustafson [12] and others, Baby CareLink’s content was re-written to support multiple learning styles. To accommodate low comprehension down to a sixth grade reading level (functional literacy), Baby CareLink offers multimedia presentation of content including streaming video, animation, and voice-over reading of content. The variety of presentation styles, simple universal graphics, and a consistent framework for navigation make Baby CareLink usable by those parents and clinicians with no prior Internet experience. A demonstration of Baby CareLink’s functions and capabilities can be accessed at <http://www.babycarelink.com>.

Baby CareLink has been deployed in a variety of health settings on the east coast and midwest of the US in both rural and urban settings. Onsite access and onsite training are provided for families. Mothers and fathers are given separate passwords and can access Baby CareLink from outside the hospital.

In a southeastern hospital serving a mostly Medicaid population in a rural setting, more than 300 parents have used Baby CareLink more than 11 000 times during the past year. Despite the common wisdom that Medicaid families do not have access to the Internet, approximately 85% of the parents access Baby CareLink from home, at work, from the library or other public access point. The median use of Baby CareLink from outside the hospital by parents is 17 separate sessions. The nurses now use Baby CareLink as the principal discharge planning tool for all patients.

In a city hospital in the midwestern US which exclusively serves a Medicaid population, experience has been equally encouraging. More than 70 parents have initiated more

than 600 secure sessions with Baby CareLink. In contrast to the rural hospital, only 35% of sessions have been initiated outside the hospital. However, staff report more frequent and longer duration visits by families, more informed questions from families, and fewer return visits of the children after they are discharged.

Experience with Baby CareLink suggests that families from all walks of life will use and benefit from collaborative tools that keep them informed and involved in the care of their children. While all parents might benefit from programs like Baby CareLink, parents from populations that are considered vulnerable have poorer health outcomes and consequently have more to gain. While gains in healthcare knowledge and medical technologies have improved health outcomes, the effective use of information technology holds the potential to further enhance care through better collaboration and communication. Better outcomes, lower costs, and higher patient and provider satisfaction will be the likely result.

## References

- [1] comScore Study Reveals Previously Unmeasured Characteristics of US Online Hispanic Population (5/7/02, comScore Networks). Available from: [http://www.comscore.com/news/cs\\_hispanic\\_050702.htm](http://www.comscore.com/news/cs_hispanic_050702.htm).
- [2] M. McGee, C. Murphy, 25 Innovators In Collaboration. *InformationWeek* December 12, 2001.
- [3] D. D'Alessandro, P. Kingsley, Creating a pediatric digital library for pediatric health care providers and families: using literature and data to define common pediatric problems, *J. Am. Med. Inform. Assoc.* 9 (2) (2002) 161–170.
- [4] D.M. D'Alessandro, C.D. Kreiter, Improving usage of pediatric information on the Internet: the Virtual Children's Hospital, *Pediatrics* 104 (5) (1999) 55.
- [5] D.K. Richardson, J.E. Gray, S.L. Gortmaker, D.A. Goldman, D.M. Pursley, M.C. McCormick, Declining severity adjusted mortality: evidence of improving neonatal intensive care, *Pediatrics* 102 (1998) 893–899.
- [6] J.E. Brazy, B.M.H. Anderson, P.T. Becker, M. Becker, How parents of premature infants gather information and obtain support, *Neonatal Network* 20 (2001) 41–48.
- [7] B. Guyer, D.L. Hoyert, J.A. Martin, S.J. Ventura, M.F. MacDorman, D.M. Strobino, Annual summary of vital statistics, *Pediatrics* 104 (1999) 1229–1246.
- [8] E.B. St. John, K.G. Nelson, S.P. Cliver, R.R. Bishnoi, R.L. Goldenberg, Cost of neonatal care according to gestational age at birth and survival status, *Am. J. Obstet. Gynecol.* 182 (2000) 170–175.
- [9] J.E. Gray, C. Safran, R.B. Davis, G. Pompilio-Weitzner, J.E. Stewart, L. Zaccagnini, D. Pursley, Baby CareLink: using the internet and telemedicine to improve care for high-risk infants, *Pediatrics* 106 (6) (2000) 1318–1324.
- [10] R.L. Goldenberg, Low birthweight in minority and high-risk women. Patient Outcomes Research Team Final Report. Agency of Health Care Policy and Research Contract number 290-92-0055, 1998.
- [11] P.F. Brennan, The computer link projects: a decade of experience, *Stud. Health Technol. Inform.* 46 (1997) 521–526.
- [12] D.H. Gustafson, R.P. Hawkins, E.W. Boberg, F. McTavish, B. Owens, M. Wise, H. Berhe, S. Pingree, CHES: ten years of research and development in consumer health informatics for broad populations, including the underserved, *Medinfo* 10 (Pt. 2) (2001) 1459–1563.