Development and Usability Testing of a Parent Decision Support Tool for the Neonatal Intensive Care Unit

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Abstract—In this paper we present the development and evaluation of a parent decision support tool for a neonatal intensive care unit (NICU), known as PPADS or Physician and Parent Decision Support. The NICU interprofessional (IP) team uses advanced technology to care for the sickest infants in the hospital, some at the edge of viability. Many difficult care decisions are made daily for this vulnerable population. The PPADS tool, a computerized decision support system, aims to augment current NICU decision-making by helping parents make more informed decisions, improving physician-parent communication, increasing parent decision-making satisfaction, decreasing conflict, and increasing decision efficiency when faced with ethically challenging situations. The development and evaluation of the PPADS tool followed a five step methodology: assessing the clinical environment, establishing the design criteria, developing the system design, implementing the system, and performing usability testing. Usability testing of the PPADS tool with parents of neonates who have graduated (survived) from a tertiary level NICU demonstrates the usefulness and ease of use of the tool.

I. INTRODUCTION

OVER the past few decades there have been significant advances in the fields of healthcare technologies and decision support. However, the use of decision support systems in the health care field has been limited. Even though the development of medical decision support systems (MDSSs) has been limited, numerous studies have shown that they have the potential to significantly improve patient care [1]-[3].

There has been a great increase in scientific knowledge in the field of health care, which has significantly improved patient care in many areas [3]. The Neonatal Intensive Care Unit (NICU) is a fast paced, high-tech environment that has evolved with the development of new technology.

Technological advances have made it possible to sustain life in infants who would have otherwise not survived just a few decades ago. As a result, the mortality rate (death rate) has significantly decreased in the last few decades; however, the rate of morbidity (survival with disability) and the length of stay for non-survivors have increased [3]-[5].

These trends of increasing survival, increasing severe complications, and increasing length of stay for non-survivors have become new issues leading to a re-evaluation of the appropriateness of certain interventions, and the allocation of resources [4],[6]-[8]. These neonatal care issues have highlighted the importance of making efficient, ethical NICU care decisions.

As healthcare is moving towards shared decision-making, and patient empowerment, parents of neonates in the NICU are more involved in making difficult care decisions. In the NICU environment the IP team is equipped with experience, technical understanding, and medical and healthcare knowledge, while parents (or guardians) know best the values of the family culture and the environment in which the infant will be raised. It is important that parents and members of the IP team work collaboratively when making difficult care decisions in the best interest of the neonate [9].

Parent participation in decision-making in this complex and technical NICU environment can be overwhelming, emotionally distressing, and confusing. Numerous literature sources have established that NICU parents often feel uncertain and dissatisfied with the decision-making process. Currently, parents in the NICU get most of their information through consultations with physicians, advice from friends and family, books and pamphlets, and their own research. It has been shown that parents turn to the Internet to augment information provided by hospital staff. A study by Brazy et al. showed that during the first week of their neonate's life, more than half of parents of premature infants spend at least 20 hours seeking information [10].

The only computerized decision-aid for parents described in the literature is the Baby CareLink tool. Baby CareLink is a commercially available Internet-based telemedicine system designed by researchers from Harvard Medical School and the Beth Israel Deaconess Medical Center [3]. The Baby CareLink tool has been shown to enhance interactions between families, staff, and community providers. However, the tool does not provide outcome predictions or decision support to aid parents in making difficult care decisions [9],[3].

There is a need to augment the current decision-making tools available to parents, provide decision support to parents, and help guide parents through the complex NICU

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environment [3],[7]. Our work aims to address the gaps in NICU decision-making by developing a computerized decision support tool that aids parents in making difficult care decisions with physicians.

II. METHODOLOGY

The methodology used for the development and evaluation of the PPADS tool followed a five step process: assessing the clinical environment, establishing the design criteria, system design, implementation with expert input, and usability testing.

The first step in the development of the PPADS tool was to assess the NICU clinical environment through a detailed literature review, and through several meetings with our clinical neonatal care experts; a neonatologist working in the tertiary level NICU at the Children's Hospital of Eastern Ontario (CHEO), and a decision support specialist / neonatal nurse working with the Champlain Maternal Newborn Regional Program (CMNRP). During this phase we increased our understanding of the NICU environment, clarified the processes used for making difficult NICU care decisions, and confirmed a need for the development of a physician-parent NICU decision support tool.

The second step in the development of the PPADS tool was to establish two sets of design criteria that were used throughout the development life cycle of the PPADS tool. The first set of design criteria consisted of general principles deemed to be important to increase the likelihood that the tool will be integrated into health care delivery. Numerous MDSSs have been developed by researchers over the past few decades. However, successful deployment has been limited and in some cases deployment has even resulted in conflict between physicians and hospital administrators [11]. Several factors, such as minimizing manual data entry, were established based on literature searches conducted on both successful and unsuccessful deployments of previous MDSSs [12].

The second set of design criteria consisted of specific components to help NICU parents participate in decision-making for difficult care decisions. These criteria of the PPADS tool are important to ensure that the decision-making needs of parents in the NICU environment are met. Several criteria, such as a need to provide the current condition of the neonate, were established through literature reviews of NICU decision-making needs, decision-making theories, patient decision-aids in the literature, International Patient Decision Aids Standards (IPDAS), and consultations with our clinical neonatal care experts [13].

The third step in the development of the PPADS tool involved designing the system architecture, components, and interface [14],[15]. The PPADS tool was developed using Drupal, a content management system. Drupal was chosen since it is a free, open-source system. It has an advanced programming interface for developers, but no programming skills are required for basic website maintenance and administration; moreover it has an extensive library of online modules and online support. The web server software used with Drupal was Apache and PHP: Hypertext Preprocessor.

The PPADS system uses three MySQL databases: a Clinical Data Repository (CDR), a Drupal database, and a Decision Support System (DSS) database. The CDR, which was developed by previous members of the Medical Information-technology Research Group (MIRG) in Ottawa, Ontario, continuously acquires data from the Admissions/Discharge/Transfer (ADT) system, laboratory results, and patient monitors, at a rate of once per minute [16],[17]. The Drupal database stores all of the user account information and content management data. The DSS database stores the information entered by the physician and parents, the outcome predictions which are based on the CDR data, and the usage log.

The fourth step in the development of the PPADS tool was the implementation of the system using the established system design and criteria. The implementation process involved several rounds of gathering feedback from our clinical neonatal experts, and incorporating changes based on this feedback into the system.

The fifth and final step was the evaluation of the tool through usability testing at the CHEO. Ethics approval for the usability testing of the PPADS tool at the CHEO was obtained from the CHEO Research Ethics Review Board. The usability testing was conducted on parents who have previously had a child who graduated (survived) from the CHEO NICU, within the last year. The study aimed to determine the tools' usefulness, efficiency, effectiveness, acceptability, and satisfaction, and involved one 45 minute session per participant. The participants were assigned a random six digit ID number, and were asked to complete a background questionnaire which asked general questions about the participants' gender, age, education level, and NICU experience. The participants then used the PPADS tool for about 20-30 minutes, performing specific tasks. After completing the tasks, participants completed a questionnaire to evaluate the tool and identify problems. Additionally, general observations were also recorded during the participants' interaction with the PPADS tool.
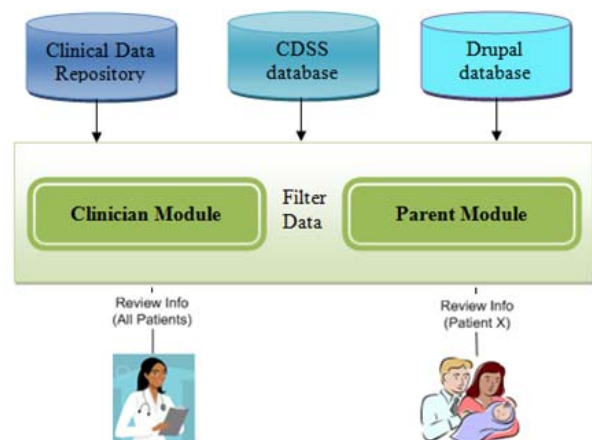

Fig. 1. Schematic illustration of PPADS system design.

III. RESULTS

A. Development Results

The PPADS tool consists of two distinct user interfaces: a clinician interface and a parent interface. Both tools are accessed through the same URL (Uniform Resource Locator), based on the user account, using any common web browser on either a desktop, laptop, or mobile device. Security of sensitive patient data has been ensured as the PPADS tool can only be accessed from inside the hospital's secure network. Each of the parent and clinician accounts have their own username and password. Parents will only have access to information which they have been given permission from the clinician to view. A schematic illustration of the system design is shown in Fig.1.

1) Clinician Tool

The Clinician tool allows the clinician to view patient information and select what information parents will be able to view.

The homepage shows a summary of important information for all patients currently admitted to the NICU. From the homepage, the clinician can access each individual neonate's patient file, activate parent accounts, search for past patients, and edit the glossary.

Each patient file contains the neonate's patient ID, name, date of birth, gender, NICU bed location, admission date, and any completed parent decision support forms. In order to minimize the amount of manual data entry, data from the CDR is used whenever possible. Some information is not currently available in the CDR, and therefore must be entered manually. To aid in entering information, each patient file contains a checkbox list of current conditions, current treatment options, and current directions of care. The

clinician is able to quickly select the information pertaining to the neonate. This information is stored in the DSS database and can be accessed by both the parent and the clinician. The patient file also contains a free-form clinician's note section. This section allows clinicians to write a notation that is specific to a given neonate.

The parent account activation module allows clinicians to activate a parent account for each neonate, and choose what information the parents will have access to. This is done using a checklist of available modules, including current conditions, current treatments, decision support forms, doctor's notes, and risk predictions.

The patient search module provides clinicians access to past patient information contained within the system. Clinicians may search for past cases using the patient name, hospital number, or by dates.

The glossary module contains definitions for many medical terms, which are made available to parents. Clinicians are able to edit the existing definitions, and can add new glossary terms as needed.

2) Parent Tool

The parent homepage contains a welcoming statement and easy navigation to five sections: current condition, current treatment, outcome prediction, decision support, and the glossary. Each parent account will only be able to navigate to the pages that have been activated by the physician.

The current condition module displays the neonate's gestational age, a list of the neonate's current conditions, and a note from the doctor. Each of the neonate's current conditions is an active link to a glossary definition explaining the condition. Hovering or clicking on the active link displays the definition.

Fig. 2. Screen shot of decision aid for deciding on a change in the direction of care.

The current treatment module displays the neonate's current therapies. Each of the therapies is once again linked to a glossary definition which provides more details.

The outcome predictions module provides parents with risk predictions for mortality and other conditions. The risk predictions are displayed in a graphical "speedometer" format and written out in sentence form to help facilitate parent understanding.

The decision support module outlines any care decision which must be made, and provides decision support to assist parents in participating in decision-making. There are numerous potential decisions to be made about the care of neonates in the NICU. One of the most difficult decisions is deciding on a change in the direction of care. A decision aid, to facilitate decision-making about a change in the direction of care, was developed as part of this work. The instrument consists of six steps which address different aspects of the decision which must be made. The instrument provides information and questions that aid in determining how one's views and beliefs affect the decision at hand. It also aids in organizing decisional information, in determining what information is required for decision-making, and in identifying what additional information is required. A screen shot of the third step of the decision aid is shown in Fig. 2.

B. Usability Testing Results

Usability testing was performed on eight parents who had a neonate who graduated from the NICU within the last year. The number of participants chosen for this work is based on previous research findings, which concluded that 8-10 participants of the representative population are required for a good in-depth usability study [18]. The usability results have indicated the usefulness, efficiency, effectiveness, acceptability, and satisfaction of the tool.

The participants found the tool very easy to use and learn. All eight participants completed all required tasks without any miss-clicks, in an efficient manner. Throughout usability testing the eight participants provided 56 positive comments and one negative comment. All eight participants indicated that they would use the tool if given the opportunity. The participants also provided rich comments on how to improve the tool. The most common suggestion was to add more information. The participants suggested the addition of glossary definitions which describe specific medications and the side effects of treatments.

IV. CONCLUSIONS AND FUTURE WORK

The development and evaluation of the PPADS tool, according to the five-step methodology outlined, has been completed. The PPADS tool has the potential to benefit future parents and physicians caring for very ill neonates in the NICU.

Future work includes performing two more phases of usability testing on parents of neonates in the NICU. The next phase should continue to assess the clinical impact on the target users of the PPADS tool by conducting a usability study on parents with neonates who did not survive NICU care. The second phase should be a prospective study to assess the tool in the NICU environment. Finally, a randomized multi-centre clinical trial should be conducted.

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