An Intelligence Risk Detection Framework to Improve Decision Efficiency in Healthcare Contexts: The Example of Pediatric Congenital Heart Disease

Fatemeh (Hoda) Moghimi
PhD student in Business IT & Logistics School, RMIT University, Australia
fatemeh.moghimi@rmit.edu.au

Professor Nilmini Wickramasinghe
Professor in Business IT & Logistics School, RMIT University, Australia
nilmini.wickramasinghe@rmit.edu.au

Dr. Hossein Seif Zadeh
Senior lecturer in Business IT & Logistics School, RMIT University, Australia
hossein.zadeh@rmit.edu.au

Abstract

Superior decision making in healthcare can literally mean the difference between life and death. Given the time pressures faced by healthcare professionals coupled with the need to process large amounts of disparate data and information to make appropriate treatment decisions, these professionals are faced with an increasingly challenging work context. We contend that such a context is appropriate for the application of real time intelligent risk detection decision support systems and try to develop a suitable model. To illustrate the benefits of risk detection to improve decision efficacy in healthcare contexts we focus on the case of Congenital Heart Disease (CHD), an area which requires complex high risk decisions to facilitate identification of appropriate treatment strategies.

1. Introduction

Effective decision making is vital in all healthcare activities. While this decision making is typically complex and unstructured, it requires the decision maker to gather multi-spectral data and information in order to make an effective choice when faced with numerous options[1]. Unstructured decision making in dynamic and complex environments is challenging and in almost every situation the decision maker is undoubtedly faced with information inferiority. The need for germane knowledge, pertinent information and relevant data are critical and hence the value of harnessing knowledge and embracing the tools, techniques, technologies and tactics of knowledge management are essential to ensuring efficiency and efficacy in the decision making process. Recognizing this[2], developed the Intelligent Continuum, a systematic approach that enables the application of knowledge management (KM) principles and tools necessary for improving the decision making processes in healthcare and to ensure that the healthcare decision making process outcomes are optimized for maximal patient benefit. The following research in progress attempts to extend this idea. Specifically, it focuses on answering the research question of how to incorporate intelligent risk detection into healthcare decision support systems. To illustrate the benefits of the incorporation of intelligent risk detection to improve decision efficacy in healthcare contexts, we focus on the case of Congenital Heart Disease (CHD), an area that is not only of significance but also involves multiple risks and critical decision making processes and hence an appropriate environment to demonstrate the benefits of our approach.

2. Background

Congenital Heart Disease (CHD) is a common health problem affecting many children around the world. The term “congenital heart disease” refers to “disorders of heart or central blood vessels present at birth” [3]. “CHD is one of the biggest killers of infants less than one year old” [4] and the risk of death remains significantly high for these patients throughout their life, with over 40% unable to reach the age of five. Unfortunately surgery is not considered a final cure, as it can result in a considerably high rate of disabilities, as well as certain other diseases for example, diabetes or various types of cancer. As well as the direct adverse impact on the patients and their families, CHD also carries significant societal and economic implications. Furthermore, infants born with complex congenital heart disease are not only at risk of serious heart-related complications, but also of developing a deadly bowel disease, regardless of the type of surgical intervention they receive for their heart [5].

In consideration of CHD surgery, it is important to consider not only immediate medical result, but also the ongoing risk of increased probability of sudden death,
exercise intolerance, neurodevelopment and psychological problems as well as long-term impacts on the family unit as a whole. This multi-faceted consideration is important because:

- The risk of late sudden death for patients surviving operation for common CHD is 25 to 100 times greater than an age-matched control population [6].
- Exercise intolerance is significantly increased in many survivors of the surgery.
- More than 50% of patients after surgery demonstrate abnormalities in neurodevelopment testing.
- Between 1-in-8 and 1-in-3 of survivors exhibit post-traumatic stress disorder (PTSD) and a further similar percentage display signs of PTSD symptoms [7].
- Children with complex CHD are rated by their parents and their teachers as being more withdrawn, experiencing more social problems and engaged in fewer physical activities.
- Fewer parents have attachment relationships with their CHD-affected infants compared to those of healthy infants [8] and parents of children with CHD are found to be overprotective, overindulgent and inconsistent in disciplining their children.
- Families of children with CHD experience more financial strain and greater familial/social stress compared to control groups [9].

We content therefore, that an Intelligence Risk Detection (IRD) model in support of better treatment decision making for this growing population of children during and after surgery can provide superior healthcare outcomes for the patient and their families. In developing such a solution, it is necessary to combine three key areas of knowledge discovery, risk detection with decision support systems (Figure 1). This is an important contribution to both theory and practice in healthcare. Since, to data this has rarely been attempted if at all.

3. Literature Review

This section outlines the major issues pertaining to the key areas of decision support systems, risk detection and knowledge discovery and their importance to the design of our proposed real time intelligence risk detection model to improve healthcare decision making processes.

3.1. Knowledge Discovery in Data bases (KDD)

Knowledge discovery in data bases (KDD) is defined as the nontrivial process of identifying valid, novel, potentially useful, and ultimately understandable patterns in data [24]. One of the most relevant applications of KDD for healthcare contexts is the Intelligence Continuum (IC) model [26]. The IC model includes but is not limited to applying the techniques of data mining, business intelligence/business analysis (BI/BA) and knowledge management (KM) to facilitate superior healthcare delivery. In order to maximize the value/utility of our IRD model and because the combined techniques of DM, BA/BI and KM are so essential in the present context, we use the IC model as the foundation for our model as shown in Figure 1.

3.2. Decision Support Systems (DSS)

Research in the use of decision support systems (DSS) in healthcare is relatively established. Furthermore, its use in medical diagnosis and clinical practice is set to increase 10-fold within the next decades [10]. Fundamentally this research covers clinical and medical aspects typically focusing on how information technology emulates and improves decision-making effectiveness for individual physicians [11]. Specifically, computer based decision support systems focus on any software designed to directly aid in clinical decision making in which characteristics of individual patients are matched to a computerized knowledge base for the purpose of generating patient-specific assessments or
recommendations that are then presented to clinicians for consideration [12]. In addition, the computer-based patient record, the Internet, shared decision-making processes, and current regulations also facilitate medical decision support systems [11]. Therefore, for the purpose of our research the literature pertaining to Clinical Decision Support Systems (CDSS) and Medical Decision Support Systems (MDSS) is equally relevant as integral to both is the use of computer systems to promote decision support to healthcare professionals.

Decision-making regarding surgery for infants with congenital heart disease (CHD) is especially multifaceted and complex. Patients may have a variety of symptoms, but are often quite functional, and therefore, it is appealing to lean towards a complete anatomical repair [13]. However, if the decision is for late repair, risks and benefits of surgery must be weighed against potential risks of not proceeding with the surgery [14]. Moreover, the decision to treat CHD with either drugs, or surgery, or a combination of both depends on a large number of factors [15].

The decision making process in the context of CHD can be divided into three phases (Figure 2). In the first phase, or pre-operation phase, the surgeon, having received enough information about the patient and his/her medical condition, makes a decision relating to whether surgery is the best medical option. Once this decision is made but before surgery, the parents must decide whether to accept or reject the surgeon’s decision in consideration of the predicted outcomes. Once parents and surgeons have agreed to proceed, in phase 2, ad-hoc decisions pertaining to the unique situations during the surgery must be addressed. Finally, in the post operating phase, or phase 3, decision making is primarily done at two levels; a) strategies to ensure a sustained successful result for the patient during aftercare and beyond, and b) record of lessons learnt for use in future similar cases.

To capture this complexity, we define two steps of decision making in three different and key phases of the decision making process for CHD surgery. The first type of decision making is called “surgical decision making” as it is primarily associated with the surgeons.

The second type is called “parental decision making” because some surgery outcomes (such as “quality of life”) directly affects the parents and therefore they have a critical say in whether to proceed with the surgery. Figure 2 shows the decision making framework we have developed based on the key phases explained above.

Although DSSs in the healthcare area is generally well discussed, unfortunately acceptance of such solutions tends to be low because doctors (the primary users) are reluctant to use computers [16]. Close consideration must also be paid to ensuring the clinical utility of any proposed solution. We contend that by incorporating real time risk detection the system is likely to then become more relevant and helpful which in turn will enhance its utility and thus adoption.

3.3. An intelligence risk detection framework in healthcare area

Surgical performance is usually indirectly measured by postoperative outcome of the initial hospital stay by means of risk-adjusted audits [17]. Although risk adjustment is important to assess performance and compare outcomes amongst individuals or institutions [18], statistical inferences alone cannot be used to determine what is considered acceptable performance [19]. Today’s available methods look at the “big picture,” from diagnosis to surgery and postoperative care [20]. It is somewhat misleading, however, to judge an individual surgeon’s performance by using postoperative outcome data such as 30-day survival or hospital survival [20]. A poor outcome can be the result of a technical error, a nursing mistake, a drug error, or substandard intensive care monitoring [20]. Additionally patients undergoing congenital heart surgery face many other types of risks affecting mortality rates during and after admissions [21].

Therefore it is imperative that surgery-driven, validated, risk-adjusted outcome analysis is employed, which can indeed lead to improvements in performance by both individual cardiac surgeons and cardiac surgery centres [22].

Risk adjustment for paediatric congenital heart operations, in itself, is challenging due to the great diversity of the patient population in terms of the diagnoses, indications for operation, the operation performed, the age at which an operation is deemed necessary and feasible, and other factors [23]. An internationally accepted procedural classification scheme, Risk Adjustment for Congenital Heart Surgery (RACHS-1)¹ [24], groups 79 different types of operations into six categories ranked in order of

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¹ RACHS-1 is risk adjustment for congenial heart disease based on these variables: risk category, age, and pre-maturity, presence of a major non-cardiac structural anomaly, gender, race, insurance volume and combination of cardiac surgical procedure.
increasing risk, as perceived by clinicians. The RACHS-1 scheme has been validated in a range of contexts [18].

Paediatric risk of mortality (PRISM) method in operative risk prediction after open-heart surgery in children is the well-known model used in predicting risks of heart surgery in children [25].

Milth et al compared performance of RACHS-1 score with PRISM score in operative risk prediction after open heart surgery in children, as the two mainstream methods of assessing risk factors in heart surgery [25]. Their study showed performance of PRISM in this large-scale, non-selected paediatric open-heart surgery patient population was poor while the discrimination power of RACHS-1 was good and in accord with other studies recently published in the literature. However, RACHS-1 failed to accurately predict death after paediatric open-heart surgery patients [25]. In the end, Milth et al suggested a different and more precise approach in predicting the outcome of the surgical procedure for these patients [25].

Based on the above, and based on an exhaustive literature review of risk detection importance in healthcare area, particularly in the case of CHD, we found that applying some IT based techniques such as knowledge discovery followed by data mining is likely to significantly increase performance of the current risk adjustment methods.

Finding relationships between risk factors as well as relationships between these factors and outcome of the surgery, an intelligent model is very likely to be more effective. Employing evolutionary intelligence solutions has the potential to improve performance of the surgery even further.

Although risk detection is an essential part of healthcare decision making, to the best of the authors’ knowledge, there exist very few intelligent systems in healthcare with specific real-time risk detection component.

Table 1 serves to summarise the relevant studies. Given the importance of risk detection in the context of CHD and the fact, to date, that real-time risk detection has not significantly been incorporated into healthcare decision support, we believe this is an essential aspect of our proposed model.

<table>
<thead>
<tr>
<th>Title</th>
<th>Technologies</th>
<th>Objectives</th>
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<tbody>
<tr>
<td>Analysis of health care data using different data mining techniques [26]</td>
<td>The potential use of classification based data mining techniques such as decision tree and association rule to massive volume of health care data.</td>
<td>In this study, our objective are to: (1) present an evaluation of techniques such as decision tree and association rules to Predict the occurrence of route of transmission based on treatment history of HIV patients. (2) Demonstrate that data mining method can yield valuable new knowledge and pattern related to the HIV patient; (3) assesses the utilization of Healthcare resources and demonstrate the socioeconomic, demographic and medical histories of patient.</td>
</tr>
<tr>
<td>Intelligent heart disease prediction system using data mining techniques [27]</td>
<td>data mining techniques, namely, decision trees, naïve bays and neural network</td>
<td>This research has developed a prototype Intelligent Heart Disease Prediction System (IH DPS) using medical profile such as age, sex, blood pressure and blood sugar it can predict the likelihood of patients getting a heart disease.</td>
</tr>
<tr>
<td>Knowledge discovery approaches for early detection of decomposition conditions in heart failure patients [28]</td>
<td>Several KD algorithms have been applied on collected data</td>
<td>They propose an innovative knowledge based platform of services for effective and efficient clinical management of heart failure within elderly population.</td>
</tr>
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4. Conceptual Model

The left-most block in Figure 3 depicts the first stage of risk assessment. The output of the risk assessment process will help in determining important surgery risk factors and also predicting anticipated outcomes based on the those risk factors.

The anticipated outcomes enable the CHD surgeons making informed decision whether to proceed with the surgery. If the decision is indeed to proceed with the surgery, all relevant information is passed on to the parents in order to allow them making the final decision regarding the surgery.

Any conflict in the decision of the surgeon and that of the parents is an indication of high-levels of risk or some negative outcome of surgery. Any such conflicts are fed back into the system for future risk assessments for the same or other patients.

After the surgery, actual outcomes are compared to the anticipated ones predicted by the system. This comparison is an evaluation process in the model ensuring continual improvement of the system’s predicting capabilities.

4.1. Risk assessment

To assess congenital heart disease surgery improvement, detecting risk factors is a useful method [3]. Although there are such methods on the risk adjustment for CHD surgery as RACH-1 [29] and also Wilson & Cleary [30], they are based on one or some dimensions of CHD surgery risks while to improve the decision making process by risk detection, we will need to develop a multidimensional risk model to apply risk assessment.

Therefore, to address this issue, after identifying some critical risk in the literature, we will seek expert input in two distinct stages, which required different degrees of the CHD specialists’ involvement in risk assessment.

Their model is based on: physiology, symptoms, function, general health perception, health related to quality of life.

In the first stage, the CHD specialists in a focus group are presented with risk factors identified in the literature. The experts will then nominate (or introduce) some main risk dimensions to be used in the surgical decision making process. In the second stage, the CHD surgeons are asked to complete this risk assessment checklist to assess the risk factors and also define the relationships between these factors or between these factors and some actual or anticipated results, and also anticipated value range of the risk factors in order to define some relevant KPIs (key performance indicators). Moreover, we document the surgeons’ and specialists’ recommended additional procedures and ask them to assess the responses provided by our subjects. The risk assessment process is shown in Figure 4.
4.2. Risk detection using knowledge discovery

To incorporate an intelligent technology into the proposed risk assessment process, we suggest a data mining process followed by knowledge discovery. In the research case, the data types have a significant impact on the data mining tasks. Hence, after finishing the data collecting phase, the suitable tasks will extract such as neural networks and association rules. To apply the necessary data mining techniques, developing and then implementing the model, after the risk assessment process, we will design a small database that included CHD patients’ data and also some data to show risk factors. Then we move through step 1 to step 6 (below).

The steps are:

**Step1.** Understand business requirements, dataset structure and data mining task Knowledge-Rich Data Mining in healthcare Risk Detection. Designing a dimensional data mart will be more effective to apply data mining tasks on this data mart.

**Step2.** Prepare target datasets: select and transform relevant features; data cleaning; data integration. Communicate any findings during data preparation to domain experts.

**Step3.** Train multiple data mining models in randomly sampled partitions using Clementine or Rapid miner.

**Step4.** Evaluate data mining models using a set of performance metrics.

**Step5.** Discuss the data mining results with domain experts. Explore potential patterns from data mining results. If identify new risk factors or patterns, communicate the rule(s) with decision makers and determine the appropriate actions.

**Step6.** Go back to Step 1 if new business questions are raised during the process or new KPI, rule(s) or risk factor are discovered after comparing the actual and anticipate results. Otherwise, finish and exit the process.

Data from a large hospital in Melbourne, Australia will be used to operate the procedure described above. Input to the system will be a dataset of CHD surgery risk factors, and the outcome will be decision functions results of performance metrics; new and revised risk factors.

4.3. Applying anticipated and actual results

The decision making process for CHD patient surgery is presented in section 3.2. Based on this framework, two types of decision making, surgical and parental, are defined. Our model (figure3) will enable contemporaneous and real time detection of risks factors and prediction of surgery results. The results will bear a significant importance in forming surgical and parental decisions.

In the proposed conceptual model, to evaluate a risk detection process, the actual results will be compared with the anticipated results. This is because sometimes actual results present some new risk factors or new measurement to assess the risk factors. The business intelligence reporting tools would be the best solution to create a final report to show some important items, and finally apply them to the risk assessment process, for next iterations of evaluations.

5. Discussion

The proceeding served to outline a research in progress that is examining the merit of combining real time intelligent risk detection with decision support in a healthcare context. The case of CHD was chosen because of the complex nature of the decision making in this context as well as the many risks inherent with these decisions.

The lack of interaction between healthcare industry practitioners and academic researchers makes it hard to discover CHD risks, and limits opportunities for the application of data mining techniques, and hence weakens the value that knowledge discovery and data mining methods may bring to healthcare risk detection.

The CHD risk detection has many dimension and perspectives that their main focuses are usually on pathological process, physiological variables, some general health perceptions, social paradigm and also quality of life [30]. So, detecting risk factors in all of these dimensions is not easy but based on our two approaches to assess the risks, with contribution of some CHD specialists, we try to cover some main dimensions.

To the best of our knowledge, this is the first study that directly examines the benefits of real time risk detection and outcome prediction in order to augment decision making process in healthcare area.

Also, using KPIs (key performance indicators) as a set of metrics is a novel idea to control the risk factors, finding its level and defining their relationships together, also with the other factors in such healthcare context. Furthers, KPIs will be so effective to monitor some key items during surgery for surgeons. It will be one of the valuable outcomes through this research that will be effective for CHD specialist during all stages of patients’ treatments.

Moreover, this research has the potential to contribute to understanding of the usefulness of involving CHD specialists in designing an intelligent model when they

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3 A commercial software for data mining
4 An open source software for data mining
has identified risk factors during the planning stages of the risk assessment and risk detection.

Additionally, it should reduce the burden of CHD surgery on its patients, their parents and society is the other strategic benefits that will examined.

Being continues, is yet another advantage of this model. By comparing anticipant results and actual outcomes, risk factors will be amended to improve future predictions.

An important feature of our IRD model is the integration of the three IT solutions to solve a clinical issue in the definition and assessment of “outcomes” in patients with CHD, combined by some assessment measures. The next steps include that the theoretical framework developed here needs to be tasted in future research. However, empirical testing of the framework is likely to face a number of challenges such as:

1) The IRD model developed here will be used to identify common metrics for measuring the risk factors.

2) We have found a few instances where hospitals have well developed capabilities to develop and implement an intelligent model. However, our field research to date has found that the majority of hospitals who have implemented an IT infrastructure are employing some computerised clinical decision support systems (CDSSs) mainly to improve practitioner performance [31].

The transformation of the healthcare domain to develop capabilities to apply intelligence models to detect risks is likely to accrue over an extended period of time and may be evident only in case studies. The willingness of hospitals to provide the access required for conducting such in –depth case studies is another challenge that needs to be overcome.

6. Conclusions

In this paper, we propose an intelligence risk detection model using knowledge discovery methods. Intelligent risk detection is a particularly challenging area for the healthcare industry while relatively common for fraud detection in finance, diagnosis in industry, and affect analysis in chemistry. This not only because building cases of training sets is difficult, but also because the cases may have many forms, causes, and unknown relations. We propose the application of knowledge discovery to high-level surgery risk detection and outcome prediction. The model designed is based on two steps of decision making process (surgical and parental) and, includes a decision support system which is suitable for high concentration prediction. Continual model update inherent in the proposed system results in adaptive and more accurate risk detection and outcomes prediction capabilities compared to fixed model. This study confirms that the selection of the risk detection, prediction by knowledge discovery and then decision making are also very important for CHD surgical decision making process. The next phases for this research are to trial the model in appropriate clinical settings.

In closing, we contend that real time intelligent risk detection appears to be critical for many areas in healthcare where complex, high risk decision must be made and thus call for more research in this area.

References


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