Assessment of Parents' Priorities and Satisfaction with Care in the Pediatric Intensive Care Unit

Thesis

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دراسة تقييم أولويات و مدي رضا الوالدين عن رعاية أطفالهم في وحدة الرعاية المركزة للأطفال

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Abstract

Background: Evaluation of patient satisfaction and responding to patients' priorities is a key domain in quality of care improvement.

Objective: To identify parents' priorities and satisfaction with care in the PICU and to assess staff ability to fulfill parents' needs.

Design, setting and participants: the study took place in Ain Shams University children's hospital, in the PICU. We approached 104 parents of children admitted in PICU. face to face interview questionnaire was used in two situations, ***first*** at admission in the pediatric intensive care unit to identify their priorities about care and **second** after transfer to the inpatient departments to assess their level of satisfaction with care.

Results: 95 of parents responded with 91.3 % response rate in first situation and 81% response rate in second situation. The majority of responders saw most aspects of care as important. The most important priorities were those related to professional attitude domain (mean = 4.82) followed by care and cure, and information domains (mean =4.70) while organization domain had the lowest score (mean =4.36). Regarding parents' satisfaction, "care and cure" was the dimension showing the highest satisfaction score, (mean=4.16, SD =0.62), followed by professional attitude (mean=4.15, SD=0.56); while parental participation and information had the lowest level of satisfaction (Mean=2.58 and 2.29) respectively. The greatest gap between satisfaction and priorities was in items related to parental participation and information, while parents' needs were fulfilled in items related to "care and cure" and professional attitude.

Conclusion: Parents' priorities and assessment of their satisfaction rest heavily on communication between physicians and parents and this highlights the importance of good communication with the parents and the need for their involvement and participation as well as partnership between parents and health care professionals.

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List of Abbreviations

AACH : American Academy on Communication in Health Care

AAP : American Academy of Pediatrics.

CCFNI : Critical Care Family Needs Inventory.

ICU : Intensive Care Unit.

LOS : Length of Stay.

NICU : Neonatal Intensive Care Unit.

PICU : Pediatric Intensive Care Unit.

PRISM : Pediatric Risk Of Mortality.

PIM : Pediatric Index Of Mortality.

IQR : Inter-Quartile Range.

ANOVA : Analysis Of Variance.

SPSS : Statistical Package for Social Science.

Introduction

Interest in the area of patient satisfaction in health care was generated almost half a century ago. Early reports in the 1970s demonstrated the relationship between patients and professionals followed by a series of studies interested in the patients' view of medical and nursing care. In the 1980s, the concept of quality of care became a major issue in monitoring and improving health care, consequently and due to the public exerting its influence in health care, patients' opinions became an important issue in the assessment of the quality of service. Today's health care is influenced by politics, health care insurance, and patient organizations to provide a more patient-driven care. As a response to this demand and the incentive of the health care professionals for continuous quality improvement, a quality gap was recognized between theory and practice ***(Latour et al., 2005).***

The most important outcome of pediatric care is the improvement of the child's health or reduction of symptoms. However parents' satisfaction is associated with such central outcomes, including adherence to the therapeutic regimen and understanding of medical information, that parents' satisfaction with care can be considered a good proxy variable for some important aspect of quality of care ***(Ammentorp et al., 2005).***

As a result of managed health care and competition in health care delivery, hospitals are experiencing increasing

pressure to use surveys as one means of evaluating performance. Patient satisfaction or parent satisfaction in case of pediatrics, is often assessed as a means of evaluating the success or impact of quality improvement efforts ***(Mcpherson et al., 2000).***

Various approaches have been initiated to improve quality of care. As generally accepted quality performance measurements were lacking, an international project defined a set of quality of health care indicators, including patient-centered care with empowerment of the patient and family. Consequently, patient satisfaction was then gradually recognized as an important tool to evaluate healthcare system. Over the past few decades, integration of patient and family perspectives in clinical practice evolved slowly. There were some early initiatives concentrating on the needs of patient and family members, but the evaluation tools used did not always take into account their experiences ***(Latour et al., 2008).***

In the critical care setting, family involvement and support are particularly important. Evidence is accumulating that improvements in family satisfaction have a positive impact on patient outcome. When relatives are given full and honest information in an understandable and timely manner, and believe that their family member is being treated with skill and compassion, satisfaction levels rise ***(Alison Brown and Mohammed Hijazi, 2008).***

Various strategies and models have been developed to improve the quality of care. Initiatives such as evidence-based medicine and evidence-based nursing, Quality improvement circles and clinical performance indicators have been found valuable. Less attention has been given to empowerment of patients and families as a means of increasing health care standards based on their needs. A major challenge for health care workers is putting patients in the center of care, giving them autonomy, and accepting them as a partner of care. Professionals therefore need to find methods to empower patients. In pediatric intensive care unit most children may be unable to express their needs and experiences. Here the experiences of parents are recognized as being fundamental for the definition of quality. In this perspective the principles of family-centered care mandate incorporation of parents in daily care. Subsequently, measures of parent satisfaction become a valuable tool in establishing a family-centered and parent-driven care model that would benefit quality of care ***(Latour et al., 2008).***

Advances in technology and in medical, nursing and allied health practices have led to increased survival of critically ill children. The management of these children (and their families) is a continuing challenge for the multi-disciplinary term in pediatric intensive care. Maintaining and developing clinical standards for quality care is of key importance to health care providers. In pediatric services,

parental satisfaction is an important outcome issue and one way of evaluating the quality of service ***(Haines and Childs, 2005).***

Increasing emphasis is being placed on patient-centered outcomes as an important step toward improving the quality of clinical care. These outcomes include physical functions, psychological well-being, quality of life, and patient satisfaction. Outcomes as assessed from the patient's perspectives have been accepted as valid, important, and standard indicators of quality of care ***(Andrew et al., 1999).***

There is a move from prescriptive medicine to collaborative medicine. Beliefs that the doctor should be the repository of scientific health knowledge that is dispensed to the patient when needed are changing. Ideas that health is something which health professionals and consumers create together are gaining currency. A new language has been sought to replace a relationship of patient compliance with that of patient collaboration and to describe patients as co-producers of health. While there are differences between patients, today patients are more likely to be conceptualized as active decision makers, rather than passive recipients of decisions made by others ***(Draper et al., 2001).***

Aim of the Work

The objectives of this study are to:

1. Identify parents' priorities with pediatric intensive care at admission.
2. Assess parents' satisfaction with care provided in the pediatric intensive care unit after transfer to the inpatient departments.
3. Measure the gap between priorities and satisfaction to assess professionals' ability to provide care and treatment that fulfill parents' needs.

Chapter (1)

Family-Centered Care and the Pediatrician's Role

Family-Centered Care: Definition and its Importance in Pediatrics

• ***Family-centered care***. An innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers. It incorporates the patient, the health care provider, and the family in all aspects of care.

• ***Heart of Pediatric family-centered care***. The belief that health care providers and the family are partners working together to best meet the needs of the child. Parents and family members provide the child's primary strength and support. Their information and insights can enhance the professional staff's technical knowledge, improve care and help design better programs and friendlier systems ***(Neff et al., 2003).***

The core concepts of patient- and family-centered care

- **Respect and dignity.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and