

УДК 614.253.52:616-07(075.8)

Battalova Kuralay¹, Hoppia Hanna², Ospanova Dinara^{1}*
¹Kazakh medical university of continuing education, Kazakhstan
²JAMK University of Applied Sciences, Finland

PERCEPTION OF NURSING CARE BY PARENTS AT CHILDREN'S HOSPITALIZATION

SUMMARY

The illness of a child is emotions stress on both families and child. Quality of nursing care from the parents' perspective plays an important role in the development and improvement of health services performance and image. Parent or patient satisfaction is significant indicator that evaluates the care quality provided by healthcare services. There are analyzed study by finding out parent's perceptions and expectations about needs of infants with congenital heart disease during hospitalization in pediatric cardiac surgery department for improve quality of pediatric nursing. Because parents are the main stakeholders and observers of the nursing care; they are valuable source of information perceptions delivery of nursing care. These perspectives of theirs can be used to shape effective solutions and target practice improvements in the care-delivery experience.

Key words: nursing care, the perception of the child

Introduction. Hospitalization is a stressful event for parents, which can also impact children negatively by threatening children's sense of wellbeing, security, independence, and self-control (Hockenberry & Wilson, 2011). The nurse is usually constantly beside the patients, communicating directly with their parents and therefore always take into account their mental characteristics, feelings, experiences, judgments and their psychosomatic state. Patients and families are viewed as valuable source of information to explain the impact of their children illness on their lives and the quality of the care they received by the family. Perspectives of theirs can be used to shape effective solutions and target practice improvements in the care-delivery experience (Vincent & Davis, 2012). The illness of a child can have a traumatic effect on both families and child. Quality of nursing care from the parents' perspective plays an important role in the development and improvement of health services performance and image. Parent or patient satisfaction is significant indicator that evaluates the care quality provided by healthcare services (Tsironietal, 2011).

Main part

Congenital heart disease (here in after Ch D), a major cause of serious morbidity and mortality, is common. It is usually defined as clinically significant structural heart disease present at birth (Moons et al 2004, Karsdorp et al 2007). The incidence of congenital heart disease is similar in all countries (Nicolos 2007). Ch D are the 1 birth defect in UK affecting 8/1000 live births (office for national Statistics 2013).

The reality is that a diagnosis of ChD can happen to anyone (BhF 2008b) and can profoundly change the family's response to the child (Uzark et al 2008). One families can become overly protective of the infant and others distant, which may warrant further investigation. Chronically ill children negatively affect both mothers and fa-

thers (Knafl&Zoeller 2000). A child's physical or mental disability can mean that families have to meet lifelong care needs and witness their child experiencing periods of suffering (Mussatto&Tweddell 2005). Some families have to manage regular outpatient appointments (Smith.,2011).

Researcher (Zani, Golias, Martins, Parada, Marcon & Tonete, 2013) conducted a systematic review to study the feelings of parents whose children had serious health problems. The main feelings experienced by the family were: guilt, pity, fear, anger, helplessness, disappointment, incomprehension, and mourning due to the loss of its idealized child. Specialists came to the conclusion that parents have contradictions because of the contraposition between the idealized child and the actual (Silva, et all.,2014, 162-70). Here, health professionals are interlocutors in this process of conflicts experienced to help solve the internal conflict of parents (Zani, Golias, Martins, Parada, Marcon & Tonete. 2013, 269-278).

Another study highlighted family stress as a result of medical diagnoses, with regard to therapeutic decisions and in response to the care required by children with congenital heart disease in terms of facing the resulting limitations in their everyday life (Lan, Mu & Hsieh 2014, 162-170). These studies are of great value to nursing professionals, because they demonstrate the importance of nursing care in relation to emotional support and health education in order to assist the family to adapt to the health-illness transition process of the child (Robertson-Malt, Chapman & Smith. 2007; 13:132-8).

Diagnosis can also represent a huge dilemma for the family, causing conflict between individuals and feelings of guilt particularly during the decision-making process (termination, reconstructive surgery or palliation). The impact on the family is proportional to the severity of the defect an inherent Ch D. Disadvantage associated with surgical correction is that some infants can experience

*d.ospanova@kazmuno.kz

complications of surgery years later, which can prove to be a significant burden for child and family. This is a time of great stress for parents. Pre-operative effects on the family on diagnosis of ChD, parents can experience a mixture of shock, disbelief, fear, blame, anger and sadness (Pye&Ggreen, 2003). Care following diagnosis can be life changing, instability and possibly chest re-exploration.

During the post-operative period, complications for the family infection may be acquired in hospital, including ventilation-associated pneumonia and blood infection associated with invasive line placement. Most families report an overwhelming feeling of helplessness, they need to be reminded that they provide vital emotional support to their child (Papastavrou, Efstathiou, Tsangari, Suhonen, Leino & Kilpi&Patiraki, 2012). To meet care needs, professionals must recognize the continuing effects the defect may have on the family and the variables that influence these from diagnosis onwards, including ethnic origin, social class, religion and access to a specialist centre.

Nurses have a central role in the care of sick infants; they can alleviate parental stress by establishing caring relationships (Papastavrou, Efstathiou, Tsangari, Suhonen, Leino & Kilpi&Patiraki, et al. 2012). Sharing knowledge and information, paying attention to supporting parents psychologically and physically, involving parents in decision-making (Bragadottir&Reed, 2002). Poor relationships with nursing staff can be a source of stress when there are discrepancies between expectations and perceptions amongst nurses and parents (Latour, van Goudoever, Duivenvoorden, van Dam, Dullaart&Albers, et al., 2009).

Parents', physicians', and nurses' perceptions of suffering overlap but also show important differences. Differences found seem to be rooted in the relation to and kind of responsibility (parental/professional) for the child (Jasmine. T., 2009). The child's illness, suffering, and hospital admission cause suffering in parents. The aim of treatment and interventions in medicine is to cure or stop a decline in health status while, at the same time, preventing or relieving suffering (The goals of medicine: setting new priorities (1996) Hastings Cent Rep). Sometimes medical treatment is considered as only augmenting suffering and, in that sense, causes burden without benefit. In these cases, treatment may not be initiated or may be withdrawn in order to all eviate or prevent suffering. As well as medical stuff, parents are observers and participants in the treatment process of them children.

Systematic Review Golfenshtein N. et al. of the literature yielded 66 observational studies investigating sources of parenting stress in parents of young children with congenital heart defects, cancer, and Autism Spectrum Disorder. The stress parenting responsibilities place on parents increases in situations involving pediatric illness, and there for can potentially interfere with the normal family life. Stressors were categorized, and then analyzed in light of the diagnostic characteristics of the populations in focus. Findings indicate that parents across all illness

groups experience increased levels of parenting stress. The parents' perception of the quality of nursing care was also studied. Quality of nursing care from the parents' perspective plays an important role in the development and improvement of health services performance and image. Parent or patient satisfaction is significant indicator that evaluates the care quality provided by healthcare services (Tsironietal, 2011).

Several studies has been conducted on parents and nurses perception of family centered care (Okunola.I., et all, 2017, Page 67-76) This study by Okunol and co-authors analyzed several studies and made general conclusions. Study have shown there is no significant relationship between nurses' characteristics (age and years of peadiatric experience) and their perception of Family centered nursing behaviours. These findings provide concrete information as regards the Family Centered Nursing Care behaviors, the parents of hospitalized children would like to experience and caring behaviors nurses perceived as important for family centered care, they should include in their daily practice.

The second outcomes for this study revealed there is statistical differences in the perception of Family Centered Nursing Care behavior by age and level of education but length of hospital stay did not influence it. This finding could be because most parents had a previous experience in the hospital with other siblings of the sick child. Kam etal (2008) reported that age and length of stay did not explain the differences between the responses of parents of hospitalized children with sickle cell disease who perceived their child's care as of lower quality than parents of children with cancer. This differs from the study of Commodari(2010) who reported that length of hospital stay and age influenced the respondents perception of stress and level of anxiety.

During hospitalisation, parents have indicated that they are treated as an outsider; a feeling that can heighten their sense of helplessness and powerlessness. Having a sick infant, in particular an infant who requires surgery or a medical intervention, can be disruptive and stressful for parents (Heermann, Wilson & Wilhelm 2005). An understanding of parental needs is essential to the development of effective nurse-parent relationships and to help minimise parental stress (Lam, Spence, & Halliday. 2007).

The most stress caused parents identified insufficient information regarding tests and treatment and uncertainty as to whether nurses would call them about changes in their baby's condition. Helping nurses to understand the parent perceptions of pediatric intensive care hospitalization may assist nurses with addressing the need to humanize the experience.

Other qualitative study describes parents' perceptions of nurses' caregiving behaviors in a Pediatric Intensive Care Unit (PICU) in the Midwestern United States. Parents reported nurses engaged in nurturing and vigilant behavior, namely showing affection, caring, watching, and protect-

ing. Parents' reports suggest that the best nursing behaviors are those that facilitate and complement critical aspects of the parental role, thus reinforcing family integrity during a time of turmoil and uncertainty. Incorporating this knowledge into practice contributes to nurses' understanding of PICU hospitalization as a family event, and also helps to inform interventions to improve family-centered care in the PICU (Patricia, Tomlinson, Kirschbaum & Harbaugh, 2014). Satisfied health care consumers are known to show better rates of compliance with treatment regimens and be more willing to seek health care services (Greeneich et al., 1992; McMillan, 1987; Naylor, Munro, & Brooten, 1991). The findings of this research study support the need for nurses to explicitly ask consumers (patients and families) whether or not their expectations of nursing care are being met. For unless nurses ensure that the care they provide is consistent with what consumers want, nurses risk basing nursing interventions on assumptions and erroneous perceptions and consumers are unlikely to be satisfied. (British Columbia's Children's Hospital, Vancouver.)

Parents of sick infants who require neonatal surgery or who have a cardiac condition which may require surgery often face a very stressful and difficult time (Robertson-Malt, Chapman & Smith 2007). Finding out how parents view their child's hospital experience should be of great importance to hospitals caring for children in the current health care environment. Internal motivation, external regulation, and competitive pressure all compel hospitals and health care organizations caring for children to focus on improving the quality of care they provide (Lan & Hsieh, 2007). Because parental satisfaction is an important outcome of pediatric care, hospitals can try to identify and respond to the concerns of parents as one strategy in an overall program of quality improvement (Omari, AbuAlRub, & Ayasreh, 2013). These issues are also actual for Kazakhstan where no research has been conducted in this area. Also the decision of such questions as quality of treatment or satisfaction from the received treatment often depends by the expectations and perceptions of patients and their families, not only successful of the treatment process. Currently the role of nursing staff in this matter is increasing because the responsibility is already spreading not only for saving the baby life but also for keeping a comfortable emotional environment in the family.

Conclusions: In conclusion finding out parent's perceptions about needs of infants with congenital heart disease during hospitalization in pediatric cardiac surgery department is necessary for improve quality of pediatric nursing. Because parents are the main stakeholders and observers of the nursing care. Parents' reports about their children's care can also efficiently provide information about processes of care compared with resource-intensive methods such as medical record review or videotaping. The criteria for the quality of nursing care cannot be improved without their opinion. As a result, we hope that carrying out of similar researches in Kazakhstan this, being one of

the pilot projects in Kazakhstan, will help to identify the problematic issues of the nurse-the patient's family and the ways of their solution for improvement delivery nursing care.

REFERENCES

- Homer, C., J., MD, MPH; Marino, B., RN, PhD; Cleary, P., D., PhD; Alpert, H., R., MPM; Barbara Smith, MBA; Constance M. Crowley Ganser, MS, RNC; Robert M. Brustowicz, MD; & Donald A. Goldmann, MD. 2004. Quality of Care at a Children's Hospital. The Parents' Perspective, Issues in Comprehensive pediatric nursing, Volume 27
- 1 Golfenshtein, N., MHA, Einav, S., PhD, MHA, BA, RNb, & Medoff-Cooper, B., PhD, RN, FAANA, 2016. *REVIEW ARTICLE Investigating Parenting Stress Across Pediatric Health Conditions - A Systematic Review*. COMPREHENSIVE CHILD AND ADOLESCENT NURSING, VOL. 39, NO. 1, 41-79
 - 2 Hopia, H., MNSc, RN, Tomlinson, P., PhD, Paavilainen, E., & A. Stedt-Kurki, P., PhD, RN Professor, 2005. *Child in hospital: family experiences and expectations of how nurses can promote family health*, Journal of Clinical Nursing, 14, 212-222
 - 3 Heywood, H., & Sandywell, B., 2000. *Interpreting Visual Culture: Exploration in the Hermeneutics of the Visual*. London & New York: Routledge, 104-7.
 - 4 Neich, R., & *Painted Histories*. 1994. *Early Maori Figurative Painting*. Auckland: Auckland University Press, 65
 - 5 Konstantynowicz, J., Marcinowicz, L., Abramowicz, P., & Abramowicz, M., 2016. *What Do Children with Chronic Diseases and Their Parents Think About Pediatricians? A Qualitative Interview Study*. Matern Child Health J 20:1745-1752
 - 6 Lam, J., Spence, K., & Halliday, R., 2007. Parents' perception of nursing support in the neonatal intensive care unit (NICU). Neonatal pediatric and child health nursing. VOL. 10 NO. 3
 - Lee, B., Harbaugh, P., Tomlinson, P., & Kirshbaum, M., 2009. PARENTS' PERCEPTIONS OF NURSES' CAREGIVING BEHAVIORS IN THE PEDIATRIC INTENSIVE CARE UNIT. *Comprehensive child and adolescent nursing*, Pages 163-178 | Published online
 - 7 Mortensen, J., RN, Simonsen, B.O., RN Eriksen, S.B., MSc, Skovby, P., MKS, & Dall, R., MD, 2015. *EMPIRICAL STUDIES Family-centred care and traumatic symptoms in parents of children admitted to PICU*. Nordic College of Caring Science, 29; 495-500
 - 8 Nieves, J.A., Uzark, K., Rudd, A., Strawn, J., Schmelzer, A., & Dobrolet, N., 2017. *Interstage Home Monitoring After Newborn First-Stage Palliation for Hypoplastic Left Heart Syndrome: Family Education Strategies improvement*. Critical Care Nurse Vol 37, No. 2. p7 2-88
 - 9 Okunola, I., RN, RM, BNSC, MSc, Oloagun, A.A.,

RN, RM, RPHN, PhD, Adereti, S.C., RN, Bankole, A., RN, Oyibocha, E., RN, RM, & Ajao, O., RN, 2017. *Paediatric Parents and Nurses Perception of Family – Centered Nursing Care in Southwest Nigeria*, International Journal of Caring Sciences, Volume 10, Page 67-76

10 Smith, J., BSc (Hons) MSc PhD RSCN, Cheater, F., MA (Hons) PhD RGN, & Bekker, H., BSc MSc PhD, 2013. *Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature* Health Expectations, 18, pp.452–474

11 Woodgate, R. L., Edwards, M., Ripat, J.D., Rempel, G., Johnson, S.F., 2016. *Siblings of children with complex care needs: their perspectives and experiences of participating in everyday life*, Child: care, health and development, 42, 4, 504–512

12 Abidin, R.R. & Wilfong, E. (1989). Parenting

stress and its relationship to child health care. Children's Health Care: Journal of the Association for the Care of Children's Health, 18, 114–115 Omari, F.H., AbuAlRub, R., & Ayasreh, I., R., 2013. Perceptions of patients and nurses towards Omari, F.H., AbuAlRub, R. and Ayasreh, I.R., 2013. nurse caring behaviors in coronary care units in Jordan. Journal of clinical nursing. 22(21-22), pp.3183-3191.

13 Kam, J., Panepinto, J., A., Brandow, A., M., and Brousseau, D., C., 2008. Parental perception of quality of hospital care for children with sickle cell disease. Wisconsin Medical Journal (WMJ), 107(3), p.131

14 Lan SF, Mu PF, Hsieh KS. Maternal experiences making a decision about heart surgery for their young children with congenital heart disease. J Clin Nurs. 2007; 16:2323-30

ТҮЙІНДІ

Баланың ауруы тек балада ғана емес, сонымен қатар бүкіл отбасында да эмоционалды шиеленісті тудырады. Ата-анасының тұрғысынан мейірбике күтімінің сапасы медициналық қызметтің тиімділігі мен имиджін дамыту мен жетілдіруде маңызды рөл атқарады. Ата-аналардың немесе пациенттердің қанағаттанушылықтары медициналық қызметтердің сапасын бағалайтын маңызды көрсеткіш болып табылады. Мақалада ата-аналардың мейірбикелік қамқорлық тұжырымдамасын қабылдау және туа біткен жүрек ақаулары бар нәрестелердің қажеттіліктеріне қатысты үміттерін түсіндіру арқылы өткізілген зерттеулер талданды. Зерттеулер балалар кардиохирургия бөлімшесінде ауруханаға жатқызу кезінде жүргізілді. Зерттеу нәтижелері педиатриялық мейірбикенің сапасын жақсартуға бағытталған. Ата-аналар мейірбикелік күтімнің негізгі мүдделі тұлғалар және бақылаушысы болғандықтан, олар мейірбикелік күтімді қабылдау туралы маңызды ақпарат көзі болып табылады. Осы зерттеулердің нәтижесі тиімді шешімдерді қалыптастыру және мейірбикелік тәжірибенің тиімділігін арттыру және емдеу мәдениеті үшін пайдаланылуы мүмкін. Бала күтімі туралы серіктестердің берген есептері медицина жазбаларын немесе бейнематериалдарын қарау сияқты ресурстарға негізделген әдістермен салыстырғанда, мейірбикелік күтім процестеріне қатысты ақпаратты тиімді түрде бере алады. Мақалада көтерілген мәселелер Қазақстан үшін өте өзекті, өйткені бұл салада ешқандай зерттеулер жүргізілмеген. Қазіргі уақытта осы мәселе бойынша медбикелердің рөлі артып келеді, өйткені медициналық қызметтердің сапасы тек баланың өмірін сақтап қана қоймай, сонымен қатар отбасында жайлы эмоционалды жағдайды сақтауға бағытталған.

Кілт сөздер: мейірбикелік күтім, баланы қабылдау

АННОТАЦИЯ

Болезнь ребенка вызывает эмоциональное напряжение не только у ребенка, но и у всей семьи. Качество сестринского ухода с точки зрения родителей играет важную роль в развитии и улучшении результативности и имиджа медицинских услуг. Удовлетворение родителей или пациентов является важным показателем, который оценивает качество оказываемых медицинских услуг. В статье нами проанализированы исследования, проведенные путем выяснения восприятия родителями концепции сестринского ухода и их ожиданий относительно потребностей младенцев с врожденными пороками сердца. Исследования проводились во время госпитализации в отделении детской кардиохирургии. Результаты исследований были направлены для улучшения качества педиатрического сестринского дела. Поскольку родители являются основными заинтересованными сторонами и наблюдателями сестринского ухода, то, соответственно, они являются ценным источником информации о восприятии получения сестринского ухода. Результаты данных исследований могут быть использованы для формирования эффективных решений и повышения эффективности сестринской практики и культуры оказания помощи. Отчеты партнеров об уходе за детьми могут также эффективно предоставлять информацию о процессах сестринского ухода по сравнению с ресурсоемкими методами, такими как обзор медицинской записи или видеосъемка. Раскрываемые в статье вопросы также актуальны для Казахстана, где в этой области не проводилось никаких исследований. В настоящее время роль медсестер в этом вопросе возрастает, потому что качество медицинских услуг уже ориентируется не только на спасение детской жизни, но и на поддержание комфортной эмоциональной среды в семье.

Ключевые слова: сестринский уход, восприятия ребенка