Medical Neglect by Parents and Child Health at Clinical Sites

Ji-Hyun Seo¹, So Young Choi², Hwa-ok Bae³

¹Professor, Department of Medical Education and Pediatrics, School of Medicine, Gyeongsang National University, Jinju; ²Professor, College of Nursing, Gyeongsang National University, Jinju; ³Professor, Department of Social Welfare, College of Social Sciences, Gyeongsang National University, Jinju, Korea

Objectives: Medical neglect indicates no provision of medicine or medical treatment necessary for child health. Medical neglect can put children at significant risk. Little information is available on this subject. The objective of present study is to describe characteristics of medical child neglects done by parents during the hospitalization. **Methods:** We conducted a retrospective medical record review of hospitalized children whose parents had trouble with medical staff from 2017 to 2018 at the Department of Pediatrics, Gyeongsang National University Hospital. Four cases were selected as suspected medical neglects done by parents. The children were admitted under diagnosis of enteritis (Case 1), pneumonia and cerebral palsy (Case 2), toe necrosis (Case 3), and epilepsy (Case 4). Case 1 and Case 4 were admitted to the emergency and Case 1 and Case 2 were frequently readmitted with the private insurance coverage. **Results:** All the 4 Cases were "Treatment Refusal" where the parents did not comply with medical advice. Mothers of Case 1 and Case 2 were long and often disconnected neglecting their children. They treated nurses to be caregivers. Case 3 refused medical treatment for the cause of medicine. Case 4 objected test and treatment with suspected brain impairment. The Case 3 and Case 4 were "Discharge Against Medical Advice" and Case 4 is possible "Failure To Thrive." Risk factors identified in this study are private insurance coverage, family economy, disability of the child, and education and attitude of parent(s). **Conclusions:** Medical staffs must be aware of possible medical neglect of children admitted to emergency or frequently readmitted. They also must pay attention to parents neglecting children during the hospitalization so as to prevent medical child neglects at clinical sites.

Key words: Medical neglect, Parents, Child health, Risk factors, Clinical sites

INTRODUCTION

During the last a few years, so-called 'An-A-Ki' (i.e., raising kids without medicine and medical treatment) emerged as social issue on mass media in Korea. It calls the group of parents who refuse medicine and medical treatment, or withhold medical action such as vaccination necessary for children. Their intention is to prevent misuse/overuse of medicine and side effects of antibiotics, using natural treatment instead. The problem lies in using medically and scientifically unverified extreme therapies or folk medicines. This kind of acts predicts an increased risk against child health. Further worse, they send inflicted children to kindergarten and may infect other children.

Likewise, parental refusal to medicine and medical treatment sometimes occurs at clinical sites. Some parents withhold medical actions necessary for child health for the absurd personal cause or prejudiced faith [1,2]. Some parents even discharge their children against medical advice [3,4]. All these are clearly child abuse putting children at critical risk of health, and should be reported to the Child Protection Agency (CPA) as the abuse cases. In spite of the seriousness of matter, there are no legal obligations to oppress these parents not to do so [5].

Child abuse is defined as 'physical, mental, and sexual violence or cruel act obstructing normal development or harming health and wealth of the child, and abandonment or neglect' (Child Welfare Act, Article 3 Clause 7). Neglect is different form of child abuse which does not show

Corresponding author: Hwa-ok Bae
501 Jinjudaero, Jinju 52828, Korea
Tel: +82-55-772-1245, Email: hobae@gnu.ac.kr

Received: December 13, 2019 Revised: January 22, 2020 Accepted: January 29, 2020

*This research was supported by Research Promotion Support Program funded by the Gyeongsang National University (2017-03-02).

No potential conflict of interest relevant to this article was reported.

How to cite this article:

Seo JH, Choi SY, Bae HO. Medical neglect by parents and child health at clinical sites. J Health Info Stat 2020;45(1):1-7. Doi: <https://doi.org/10.21032/jhis.2020.45.1.1>

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symptoms in a short term, compared with other types of abuse. The characteristics of the neglect make us fail to indicate the case. Particularly medical neglect done by parents at clinical sites is more difficult to be identified as abuse form [6].

Medical neglect is one of neglect subtypes indicating no provision of medicine or medical treatment necessary for child health according to the National Child Protection Agency. The American Academy of Pediatrics defines medical neglect as a failure on the part of the parent or caregiver to recognize obvious signs of serious illness or a failure to follow physicians' instructions once medical advice has been sought, resulting in harm to the child [7].

Usually medical neglect takes two forms, i.e., delay on health care and refusal of health care. Delay on health care is where the parent or legal guardian intentionally or unintentionally fails to seek timely and proper medical care for a health problem of the child. Refusal of health care is where the parent or legal guardian intentionally fails to comply with the medical advice of qualified health professionals in the treatment of a child's injury, illness, or impairment [8]. Representative form of medical neglect done by parents at clinical sites is "Treatment Refusal (TR)" and "Discharge Against Medical Advice (DAMA)."

It is reported that one in every 65 to 120 discharges from general hospitals is against medical advice in the U.S. [5]. A significant number of DAMA is also reported in an independent study in Korea, with 73 cases of DAMA (1.28%) among the total 5,681 infants in Neonatal Intensive Care Units in 1999 [9]. However, there are no specific statistics of medical neglect in Korea, although the U.S. data show that medical neglect occurs in 2.3% of all substantiated child maltreatment cases reported to Child Protective Services (CPS) in 2015 [7].

Medical neglect can cause serious harm to child health, because it is the parents, not the children, who are in control of the decision of their medical care. The delay on or refusal of treatment can have adverse consequences such as exacerbation of illness, lowered health status, and even death of the child. Thus, medical neglect is most related to child survival as main risk factor for "Failure to Thrive (FTT)" which is distinct from other types of neglect [10]. Deterioration of child health leads to continual readmission to hospitals, which is directly associated with over burden of expenditure as well as medical personnel. Children whose hospital stays were coded with a diagnosis of abuse or neglect were significantly more likely to have died during the hospitalization, have longer stays, twice the number of diagnoses, and double the total charges than

were other hospitalized children [11].

Then, why parents do medical neglect at clinical sites? Not so many studies have dealt with this topic and thus not enough information is available. From a literature review, TR or DAMA sometimes arise with trying to conceal child physical abuse and sexual abuse [11]. Parental prejudiced discipline or biased faith is another cause of medical neglect [1,2]. Low-birth weight infants or high risk infants, and insufficient insurance coverage and economic burden of hospitalization were associated with DAMA [9,11,12]. Child abandonment sometimes occur due to economic reason such as not covered by the insurance, sometimes births to unwed mothers or minor mothers, sometimes disabled children [13]. Mistrust in health care system, fear about medicine misuse or overuse, misinformation or insufficient information about medical treatment and action caused frequent TR and DAMA [14,15].

Medical neglect should be seen as a serious problem that parents deprive children of the rights of survival and development. However, it is difficult to indicate medical neglect cases at clinical sites, because it takes time to be identified, compared with other physical abuse or sexual abuse disclosing symptoms easily. Further worse, it is not easy to report to CPA, because medical staff cannot recognize treatment refusal and voluntary discharge as medical neglect and fail to collect specific evidence for the neglect cases. Particularly, medical personnel avoid reporting to CPA so as not to entangle with parents or family members for fear of aftereffect. When the medical staff perceived imminent danger to the child health, they are reluctant to move on to next steps because of several reasons such as possible disclosure of their status and threatening by them [16,17].

With few studies on this subject, little information is available about the medical neglect at clinical sites in Korea. In this context, this study aims to describe characteristics of medical child neglects done by parents during the hospitalization from a retrospective review of four suspected medical neglect cases at a university hospital. Study results will help medical staff timely and effectively respond to medical neglects at clinical sites.

METHODS

Medical records review

This is a descriptive study of medical child neglect. We conducted a retrospective medical record review of hospitalized children whose par-

ents had trouble with medical staff at the Department of Pediatrics, Gyeongsang National University Hospital, Jinju, Korea. All the pediatricians (i.e., professors, residents) of the Department of Pediatrics have held one-hour morning problem conference for average one case every Tuesday. Most cases are about the severity of the unresolved illness, but they deal with a very few troublesome cases between parent(s) and medical staff which were only four cases among the total from January 2017 to December 2018. Researchers purposively selected all these four cases as medical child neglects with the consultation of an expert in this field. We precisely reviewed all the four cases to achieve study objective.

Ethical considerations

Four records illustrate suspected medical child neglects done by parents in the hospital. Case materials and patient information have been disguised in order to protect the confidentiality. The Institutional Review Board of the Gyeongsang National University reviewed and approved the research protocol (GIRB-G18-0010).

RESULTS

Case 1

A is a 2-year and 9-month-old boy who came to emergency for vomiting. The boy showed low blood pressure, fever, high pulse, and moderately dehydrated state at admission. He was hospitalized under impression of acute gastroenteritis with moderate dehydration. Next day the boy was isolated in the first-class room with the positivity of stool Rotavirus antigen. Dehydration improved after initial hydration. During 10 hospitalized nights, several times the mother refused to check vital signs of the boy. She always excused not wake the sleeping boy. Instead the mother self-diagnosed the boy has no fever. At the 6th day, the mother excused one-hour off for her visit to clinic but disappeared and disconnected during 4 hours neglecting the boy alone in the room. Doctor tried to connect the mother but failed. Doctor explained the father of the situation who responded he could not make it. Later she excused she was in sleep with intravenous (IV) fluid. Nurses educated mother of safety nursing, medication, and health care for the boy to prepare discharge. But the mother insisted not to discharge, requiring the negativity of Rotavirus antigen. Nevertheless she still refused to do enema and to check vital signs of the boy, always excusing the sleeping boy. All the cost was covered by the insurance. The mother voluntarily discharged at the last

day of insurance coverage.

Case 2

B is a 9-year-old boy admitted to the inpatient unit with pneumonia. The boy was born to hydrocephalus, spontaneously delivered at 36 weeks' pregnancy due to fetal distress. The boy was unwanted baby of poor family with many siblings. Until the boy's birth, the mother had not any routine visits to gynecology and obstetrics. However the boy was covered by fetal insurance. Thereafter, the boy was bedridden with Levin-tube feeding during 36 weeks. The mother often left the bedside not answering nurses' call. Whenever the mother found the boy salivating with tube slipping, she blamed the medical staff for the untidy care. Nurses struggled to connect the mother to confirm dental therapy for the boy, who refused excusing her exhaustion. Nurses educated the mother to turn over the boy to prevent the bed sore on the back but nurses had to do, instead of the mother always neglecting the job. After 10 hospitalized nights, the signs and symptoms of pneumonia improved but the mother refused to discharge. Thereafter, the mother consistently refused to discharge during the insured period. On the 15th day, the boy recorded 38.5°C with high fever but the mother left the boy without any notice to medical staff. On the phone the mother refused to do blood test and X-ray radiograph. Doctor prescribed a febrifuge to bring down fever through L-tube. After 4 weeks, nurse educated the mother of health care, medication, and diet for the boy to prepare discharge. The mother refused to discharge so that the doctor had to cancel the discharge.

Case 3

C is a 2-month-old girl admitted to the emergency for swelling, redness, heating sensation, and bulla of a little toe. The girl stayed 6 nights at the hospital. At the admission, the mother reported the baby badly fretted at midnight but no external wound or bite. Toe color changed purple with sustaining dorsal arterial pulse. The baby girl was assessed as coagulopathy and compression injury. At the 2nd day, toe color did not change but bulla reappeared. Several times the mother refused the injection of fresh frozen plasma necessary for possible protein C deficiency. At the 4th day, the mother refused the follow-up blood test whenever the medical staff explained the necessity to check coagulopathy progress. Initial laboratory findings such as platelet count and coagulation test were within normal limit. The family insisted discharge of the baby girl refusing treatment of IV line for toe swelling. Medical staff

warned the risk of ischemia to other toes after discharge. The family reluctantly decided to stay at hospital but still refused to get IV line. The family also refused Echo-cardiogram checking the cause of color change. At the 5th day, the family refused enoxaparin therapy. At the 6th day, the family visited dermatology and discharged voluntarily.

Case 4

D is a 1-year and 7-month-old girl admitted to the emergency for prolonged generalized tonic-clonic (GTC) type seizure over 4 hours with high fever up to 39°C. The girl was comatose, irresponsive with spontaneous eye opening at the admission. The girl was diagnosed as status epilepticus, hypoxic ischemic encephalopathy and pneumonia. Thereafter, the girl was hospitalized during 7 weeks. The doctors planned high flow standby. At the 10th day after the signing the Do Not Resuscitate (DNR), the parent requested not to provide life support treatment. The girl did not respond to every medication with too long spasm. Spasm subsided after therapy but comatose and GTC type seizure sustained. The medical staff agreed not to do active cardiopulmonary resuscitation (CPR) but advised to check vital signs of the girl, but the parents were unlikely to accept. The parents violently opposed the need of rehabilitation, saying “why should this kind of the child receive rehabilitative therapy?” The parents requested no prescription for high blood pressure of the girl at the evening visit. The medical staff warned that no provision or discontinuation of life support treatment is a violation of the law, even though the parents signed the DNR (Do not CPR). The girl had been screaming without stopping all throughout the hospitalization. At the 33rd day, the girl screamed and doctor checked brain CT which revealed high brain pressure with progressive hydrocephalus. The parents refused operation of ventricular-peritoneal shunt at Neurosurgery Department for the girl showing increased ventricle size and diffuse brain atrophy on the follow-up CT. At the 34th day, the Department tried tube feeding for the girl who vomited after lunch. But the parents insisted regular diet. At the 42nd day, the screaming of girl was getting worse. The girl showed loss of progressed diffuse brain volume, due to HIE and progressed ventricular dilatation. The girl is the case of ventricular peritoneal shunt with tissue loss and increased ventricle size on the CT. But the parents stubbornly refused operation. The medical staff warned possible sudden death with high brain pressure. The parent voluntarily discharged next week and promised to revisit on the worse condition after discharge.

DISCUSSION

Characteristics and risk factors

All the cases in this study are clearly representing medical child neglects which were intentionally done by parent(s). All the children have chronic and complex medical conditions. In spite, the mothers of the first two cases obstructed medical actions such as checking body temperature of the child and referring the child to dental therapy (Case 1, Case 2). Both mothers often and long disappeared without notice neglecting their children in the hospital, mean while the medical staff had to struggle to connect them. While parents are disconnected, medical staff experienced difficulties in medical decisions at emergency. The parents of the second two cases not only obstructed medical actions but also voluntarily discharged against medical advice. They did not permit any test, treatment, and operation necessary for the child health (Case 3, Case 4). For the Case 4, the parents refused life support system soon after signing the DNR which can put the child in the critical situation. The parents voluntarily discharged against warnings on risk of disability and even death of the child. Conclusively all the cases are found as TR (Case 1 to Case 4), and two cases are DAMA (Case 3, Case 4). One case is possible FTT (Case 4).

What are the risk factors for medical child neglects in this study? The mother of the Case 1 had no sense of medical care and nor responsibility of the child. The mother misunderstood hospital as hotel or childcare facility and treated medical staff as maid or childcare nurse. She always excused not wake the sleeping boy but it meant not to disturb her sleeping. The mother of the Case 2 was negative to any treatment and therapy for the boy. The mother blamed the medical staff for the salivating boy with tube slipping, misunderstanding the roles of medical staff. The mother of the Case 3 had no knowledge about toe impairment. The mother showed negative attitude toward medical advice with wrong information from the mass media. The parents of the Case 4 refused all the treatment and voluntarily discharged giving up the rehabilitation of the disabled girl. The first two cases are fully covered by the private insurance. They had no difficulty to pay for the hospitalization. The mothers of the first two cases refused to discharge, using the whole insurance coverage. Meanwhile the second two cases were not fully covered by the private insurance. The parent(s) of the second two cases insisted discharge regardless of family economy. The mothers of the first three cases were relatively less educated. Medical staff had difficulty in explaining

the situation of the children and providing the education to prepare for the discharge. The parents of the Case 4 were highly educated and affluent in the economy, but they did DAMA. They felt burdensome for long hospitalization for the disabled child. All the cases proved intentional medical neglects.

Conclusively, risk factors identified in this study are private insurance coverage, family economy, disability of child, and education of parent(s), as were similarly found in the relevant studies. Prior studies report that medical neglect mostly occurs when insufficient financial resources are associated with high medical demands such as low-birth weight infants or high risk children with low insurance coverage and long hospitalization [4,9,11,18,19]. Contrarily, parents sustained medical neglect with full coverage of private insurance in this study. Parents did not discharge the children up to the last day of insurance coverage in spite of medical advice. This causes excessive medical expenditure as well as over burden on medical personnel at work.

Medical neglect occurs not only with family economy and insurance coverage but also with births of unwanted babies like disabled children [13,19]. In this study, the parents strongly obstructed the medical actions for their child with disability and discharged against all warnings from the professionals. Mistrust in health care system, fear about medicine misuse or overuse, misinformation or insufficient information of medical action were also causes of DAMA in this study, as were in other studies [14,15]. However, the most crucial factor for medical neglect was education and attitude of the parent(s) who misunderstood the true roles of hospitals and medical professionals. The serious consequence can re-

sult from medical neglect. Infection and illness may deteriorate child's health and life that will lead to readmission of the children even to death. This vicious cycle will continue with moral hazard of the parents that is why medical neglects should be detected and stopped (Table 1).

Response to medical neglects

Although the four cases in this study are clear examples of medical neglect, the medical staff seemed not recognize as the cases. All the medical staff in sympathy put up with wrongful attitudes and acts of the parent(s) in sympathy for the children. They did not indicate or educate the parent(s) of medical neglect. They could not even think about reporting to the CPA. The situation is clearly stated on the chart of the Case 2. "Several times we persuaded the parent of tube feeding, who continuously refused. It needs to persuade the parent who insists regular diet for the child." The only way to stop medical neglect was persuasion of the parent (Case 2). Although medical staff strongly warned "Even though you signed DNR, it is violation of the law to cut down the life support system or stop necessary treatment" (Case 4), but this is from the ethics of medicine not from the perspective of the medical neglect.

Medical neglect such as TR and DAMA can be indicated only by medical personnel at clinical sites. However, it is not easy to prevent medical neglects at clinical sites, as shown in the present study. First, it takes a significant time to find adverse consequences before readmission of the child to hospitals. A majority of them cannot recognize parental refusing the medical advice or voluntary discharge as medical neglect, not to mention of collecting evidence for medical neglect [20]. Second,

Table 1. Summary of medical child neglects

Characteristics	Case 1	Case 2	Case 3	Case 4
Hospitalization				
Disease	Enteritis	Brain impairment at birth	Toe necrosis	Epilepsy
Admission	Emergency, Readmission 2 weeks	Readmission 36 weeks	6 nights stay	Emergency 49 nights
Child				
Disability	-	-	-	Disability
Age and sex	2-year and 9-month old boy	9-year old boy	2-month old girl	1-year and 7-month old girl
Parent(s)				
Education	Less educated	Less educated	Less educated	Highly educated
Family				
Economy	Not affluent	Not affluent	Not affluent	Affluent
Insurance	Private insurance	Private insurance	Not covered	Not covered
Type of MN	TR	TR	TR, DAMA	TR, DAMA, FTT

MN, medical neglect; TR, treatment refusal; DAMA, discharge against medical advice; FTT, failure to thrive.

medical staffs who have not received any training and education have no capability to properly respond to medical neglect cases. Further, most of the medical personnel feel burdensome for conflict with parents or family members and disclosure of their identities, even though they might indicate medical neglect as the cases [16,17].

CONCLUSION

Medical neglect is under-researched and the extent of the problem is unknown in Korean academia. This study presents clear examples of medical child neglects at a university hospital. Study results have a few significant implications. Medical staffs must be aware of the possibility of medical neglects for children admitted to emergency or frequently readmitted. They also must pay attention to parents who neglect the children in the medical care during the hospitalization. Whenever they suspect medical neglects, they should be prepared to how to timely respond to the cases and how to effectively intervene in the cases. American Association of Pediatrics suggest 5-steps criteria for diagnosing child medical neglect, there is no guideline or criteria to detect and report medical neglect cases in Korean medical society [1]. According to the Guidelines for Physicians Contemplating a DAMA, careful and thorough documentation is the best defense for all cases, and documentation waiving the hospital from any responsibility if the patient leaves against medical advice should be regarded as worthless [5].

The present study has a critical limitation. We selected only four medical records of suspected medical neglect for the study, which is far from generalizability and not free from bias. Further studies are needed to corroborate the findings of this study with larger samples and longitudinal data. Nevertheless, the present study is important as it tried to identify characteristics and risk factors of medical neglect by parents and provide some empirical evidence on medical neglect occurring at clinical sites. Study results will make a significant contribution to research in medical neglect and child health and provide information to prevent medical child neglect at clinical sites.

ORCID

Ji-Hyun Seo <https://orcid.org/0000-0002-0691-3957>
So Young Choi <https://orcid.org/0000-0002-0766-2053>
Hwa-ok Bae <https://orcid.org/0000-0002-3962-6911>

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국문초록

의료현장에서 부모에 의한 의료방임과 아동건강

서지현¹ · 최소영² · 배화옥³

¹경상대학교 의학전문대학원 아동청소년과 교수, ²경상대학교 간호대학 교수, ³경상대학교 사회복지학과 교수

목적: 의료방임이란 아동건강에 필요한 약물이나 의료적 처치를 제공하지 않는 것을 의미한다. 의료방임은 아동의 건강을 심각하게 위협할 수 있다. 본 연구의 주요 목적은 입원 환아에게 발생한 부모에 의한 의료방임을 묘사하는 것이다.

방법: 2017년에서부터 2018년 사이 경상대학교병원 소아청소년과에 입원하였던 아동 가운데 보호자와 의료진 간에 문제가 불거진 사례를 선택하여 의료기록을 면밀히 검토한 결과 4개 사례가 의료방임으로 의심되었다. 아동들은 장염(증례 1), 뇌수종(증례 2), 발가락 응고(증례 3), 뇌전증(증례 4)으로 입원하였다. 증례 1과 증례 4는 응급실로 들어온 경우이며, 증례 1과 증례 2는 민간의료보험에 가입하여 빈번하게 재입원하는 경우이다.

결과: 검토 결과, 모든 사례가 보호자가 의료처방을 따르지 않는 “치료거부”에 해당하였다. 증례 1과 증례 2는 간호사를 간병인으로 인 지하고 아동을 두고 종종 장시간 연락이 두절되는 경우였다. 증례 3과 증례 4는 의료진의 결정에 반하는 “자의퇴원”이었다. 특히 증례 4는 아동의 생존을 위협할 수 있는 “성장장애”의 가능성이 엿보였다. 본 연구에서 나타난 아동의료방임 위험요인으로는 민간의료보험 가입여부, 가정경제 수준, 아동 장애여부, 그리고 부모의 교육수준과 태도였다.

결론: 의료진은 응급실로 입원하거나 빈번하게 재입원하는 아동에게 의료방임이 발생할 수 있음을 주지하고 있어야 한다. 또한 의료현장에서 발생할 수 있는 의료방임을 막기 위하여 아동을 방임하는 부모에게 주의를 기울여야 할 것이다.

주제어: 의료방임, 부모, 아동건강, 위험요인, 의료현장