

Impact of a Health Promotion Program on Parents' Knowledge About Kawasaki Disease

Chia-Hsien Su, Feng-Yuan Chang, Ching-Tien Peng¹, Chang-Hai Tsai¹,

Jeng-Sheng Chang¹

Department of Nursing, ¹Department of Pediatrics, China Medical University Hospital, Taichung, Taiwan.

Purpose. A diagnosis of Kawasaki disease (KD) in children is often associated with morbidity and sudden death due to serious cardiac sequelae of the disease. A body of literature on parents' knowledge of long-term home care for children afflicted with the disease indicates knowledge as crucial for maintaining the children's and parents' quality of life. The concept of parents regarding home care is influenced by discharge teaching in the hospital.

Methods. The sample consisted of 34 parents whose children had been admitted to the pediatric ward of a major hospital in Taiwan upon diagnosis of KD. A control group (n = 14) received routine discharge teaching; the study group (n = 20) received health promotion program. Each parent filled out a questionnaire to assess the knowledge level on the day before the child was discharged.

Results. The results of this study indicate that the program significantly increased the knowledge score of parents.

Conclusions. Our data suggest that applying this program in discharge teaching and using questionnaires to rate parental knowledge may establish a standard of discharge teaching and assessment about the disease in clinical practice. (*Mid Taiwan J Med* 2006;11:73-81)

Key words

discharge teaching, Kawasaki disease, knowledge

INTRODUCTION

According to the American Heart Association [1], Kawasaki disease (KD) is the major cause of acquired heart disease for children worldwide. Potentially serious cardiac sequelae of the disease have been closely linked to sudden death in young adults. The reason for undertaking this study was the rising incidence of the disease in Taiwan. According to current reports by the Research Group for Epidemiology of Kawasaki

Received : 26 January 2005.

Revised : 14 June 2005.

Accepted : 20 April 2006.

Address reprint requests to : Jeng-Sheng Chang, Department of Pediatrics, China Medical University Hospital, 2 Yuh-Der Road, Taichung 404, Taiwan.

Disease in Taiwan, the incidence of KD is 8.9 per 100,000 children under five years of age [2]. While statistics regarding the anxiety level of parents with children hospitalized after diagnosis of KD are not available, following discharge, large numbers of telephone inquiries were received from those parents seeking information related to the current signs of disease, joint pain or immunization [3-5]. From this has emerged the question whether existing discharge teaching of clinical practice about the disease is effective. Nursing literature reiterates that parents require knowledge of home care for ailing children, but no study has been undertaken to pinpoint the

required level of knowledge needed. Therefore, to discern the amount and depth of knowledge of KD, a health promotion program consisting of required knowledge for home care of such children was developed. This study describes the impact of a health promotion program on parents' knowledge and argues the importance of gauging their knowledge before their children are discharged.

KD affects children through physical symptoms (high fever, swollen tongue, cracked lips, severely itching skin and arthritis) and exerts stress on parents because of the constant possibility of sudden death, even after many years of remission [2-4]. No studies which have been published about the knowledge level of parents whose children suffer from KD. As children with KD may be discharged at any phase of the disease, complications arise weeks or even years later. Parents require knowledge of the signs and progress of KD, signs of cardiac complications, effects and side-effects of medication and appropriate diet for the child [5-9]. Although the disease cannot be prevented, such knowledge can make parents more capable of caring for a child in the long term [6-8]. Hence, parents must obtain adequate knowledge during the period of their children's hospitalisation [7,8].

Pediatric nurses must take responsibility for ferreting out parents' level of knowledge [10-13]. Ball et al believe that maintaining a set standard of care for children and family should be undertaken by every pediatric nurse [14]. This enables nurses to provide quality discharge teaching to meet the needs of parents so that parents can care for the children at home [15-17]. The literature indicates parental education as a priority for long-term management and care [17,18].

Due to the short length of hospitalization for children with KD, discharge teaching, organization and evaluation pose a daily challenge for pediatric nurses. Unexpected hospitalization always places enormous stress

on parents [15,18]. This distress may spawn obstacles to parental learning. Many strategies of discharge teaching can be applied such as open discussion, written instructions and questionnaires to judge the efficacy of learning before children return home. These strategies provide support to parents, minimize anxiety and motivate learning.

MATERIALS AND METHODS

A descriptive, comparative research design identified the impact of a health promotion program on parents' knowledge of KD. The research was conducted in a major hospital in Taichung, Taiwan. Parents of children admitted to the pediatric ward following a diagnosis of KD between 1 January and 30 April 1999 were invited to take part. They were then divided into control and experimental groups by nonprobability sampling. From 1 January to 28 February, parents who met the criteria of the study were enrolled in the control group; an experimental group was similarly recruited between 1 March and 30 April. This method was chosen to demonstrate experimental variation and control for internal validity, plus to clarify the direct effect of introducing special health promotion on knowledge scores [19].

In order to identify the essential information on discharge teaching that pertains to parents whose child has been diagnosed with KD, the questionnaire used in this research was designed based on the literature. The questionnaire consisted of 34 statements in three sections: a) personal information, b) knowledge relating to disease process and associated with home care, along with c) open-ended questions which sought parents' views on whether parents felt ready to go home or if they would like more information. Data were collected on the day before their children were discharged.

Sample

A purposive sample of 34 parents was obtained from a major hospital identified from the

Cardiac Children's Foundation of the Republic of China, Taiwan, which supports research on KD. To avoid data contamination from the purposive sample in the pediatric ward, data collection was divided into two periods of time. The first period involved routine discharge teaching. The following eligibility criteria were also applied: 1) Parents whose children were admitted to the pediatric department of the hospital with confirmed KD during January-April 1999. 2) Parents whose children went home after the period of hospitalization. 3) Parents who were able to give informed consent.

Instruments

Before agreeing to participate in this study, would-be participants received explanatory letters in plain language, asking volunteers to take part in the research project. A consent form required by the RMIT Human Research Ethics Committee was given to participants before being interviewed. Informed consent from the participants was obtained prior to commencing research. The questionnaire was generated by the researcher and consisted of three sections. Section A was personal information and contained seven items. Section B contained 26 questions. It was developed to reflect required knowledge of home care as cited in nursing literature for parents whose child had been diagnosed with KD [12-15,17]. The full score was 73. In order to establish content validity of the questionnaire, before the main research was performed, the questionnaire was reviewed, and then piloted. Volunteers were given the questionnaire within a structured interview to collect both quantitative and qualitative data.

Research procedure

Control Group. Fourteen parents who met the inclusion criteria of the study were enrolled in the control group during the period from 1 January to 28 February 1999. Nurses provided routine discharge teaching to participants. An individual interview was held in the paediatric ward, using a questionnaire on the day before

their children were discharged. Participants were asked to complete section A. According to the participants' answers, the researcher ticked the answer in the boxes of the questionnaire sheet to complete section B. The participants were invited to ask questions related to the disease in the open-ended questions in section C. All participants in the control group were given the information sheets when the interview had been completed.

Experimental Group. Twenty parents met the criteria of the study and participated in the experimental group from 1 March to 30 April 1999. Participants were provided with a routine discharge teaching and were also enrolled in a health promotion program lasting 50 min, which was performed weekly by the research in the ward. Participants were interviewed individually, using a questionnaire on the day before discharge. Section A was completed by participants. According to the participant's answers, the researcher ticked the boxes and summed knowledge score for participants to complete section B. Participants were invited to ask questions related to the disease in the open-ended question of section C. Participants in the control group were given the information sheets when the interview had been completed.

RESULTS

Thirty-four parents participated in this study; a Statistical Package for the Social Sciences (SPSS) was used for descriptive analysis of demographic data. Table 1 depicts demographic data for the two groups. Table 2 shows mean and standard deviation for 11 knowledge categories between the two groups. A full score of the questionnaire for parents should be 73. Participants in the control group have a low knowledge: mean score for this group was 19.28, standard deviation 3.95. The highest knowledge score for the control group is 28. Three mean scores of parents knowledge category were zero: progression of the disease, side-effects of medicine and immunization of children. It was concluded that parents who only received the

Table 1. Demographic data for two groups

Categories	Control group	Experimental group
Parents' age (yr)		
21-30	4	10
31-45	10	10
Parents' gender		
Female	7	10
Male	7	10
Parent's educational level		
High school	6	16
Associated degree and above	8	4
No. of children		
One child	2	8
Two children	10	10
Three children	2	2
Length of stay in hospital		
Four days	10	4
Over four days	4	16
Who provided most information		
Nurses	1	0
Doctor	13	0
Researcher	0	20

Table 2. Mean for 11 knowledge categories between the two groups

Knowledge category	Control group (n = 14)	Experimental group (n = 20)
Knowledge related to signs of the disease	4.2 ± 1.8*	6.5 ± 1.1
Knowledge related to the course of the disease	0.0 ± 0.0	4.0 ± 0.0
Knowledge related to physical care for child	8.4 ± 2.8	20.3 ± 2.2
Knowledge related to psychological care for child	2.5 ± 1.3	6.8 ± 1.6
Knowledge related to proper diet of the disease for the child	2.9 ± 1.1	4.0 ± 0.9
Knowledge related to effects of medicine	0.4 ± 0.5	1.9 ± 0.9
Knowledge related to side-effects of medicine	0.0 ± 0.0	3.5 ± 1.1
Knowledge regarding to the importance of follow-up	0.4 ± 0.5	1.0 ± 0.0
Knowledge related to the signs of cardiac complications	0.3 ± 0.7	4.0 ± 0.9
Knowledge related to the immunization of children	0.0 ± 0.0	1.0 ± 0.0
Knowledge related when they should contact doctor	0.4 ± 0.5	2.8 ± 0.6

*Mean ± SD.

routine discharge teaching lacked required knowledge to care for their children at home.

Because of the data contains small size and non-normal distribution, a non-parametric test is suggested for data analysis. A Mann-Whitney U test is seen as "sensitive to the central tendency and the distribution of scores for the post-hoc comparisons" [19-21]. Also, considering a statistically significant difference for group comparison to protect against a type I error, the probability value was modified to take multiple comparisons into account. Table 3 shows a non-parametric Mann-Whitney U test was chosen to

perform data analysis to verify that the special health promotion program has the effect of improving knowledge scores [20].

Table 4 records a significant difference in knowledge between parents receiving a special health promotion program and those who received routine care ($p < 0.001$) in 11 categories: signs of the disease ($p < 0.001$), course of the disease ($p < 0.001$), physical care for children ($p < 0.001$), psychological support for children ($p < 0.001$), proper diet of the disease for children ($p < 0.001$), effect of medicine ($p < 0.001$), side-effects of medicine ($p < 0.001$), importance of

Table 3. Mann-Whitney U test for the control and experimental group (N = 34)

	Mean rank	Sum of ranks	<i>p</i>
Control group (n = 14)	7.5	105.0	< 0.001
Experimental group (n = 20)	24.5	490.0	

Table 4. Mann-Whitney U test for each category between two groups

	<i>p</i>
Signs of the disease	0.001
Course of the disease	< 0.001
Physical care for child	< 0.001
Psychological care for child	< 0.001
Proper diet of the disease	0.006
Effects of medicine	< 0.001
Side-effects of medicine	< 0.001
Importance of follow-up	< 0.001
Signs of cardiac complications	< 0.001
Immunization of child	< 0.001
When they should contact doctor	< 0.001

regular follow-up ($p < 0.001$), signs of cardiac complications ($p < 0.001$), immunization of children ($p < 0.001$) and when parents should contact their practitioner immediately ($p < 0.001$). This indicates that the health promotion had a positive effect on improving the knowledge level of parents.

Some comparisons could not be made, owing to the small sample size. Knowledge scores of parents supplied with information from the researcher exceed scores of parents who received information from nurses and doctors. The results indicated that the health promotion has significant effect on the parents' knowledge of Kawasaki disease. However, the statistical difference in scores was not explained by parental age, gender, educational level, number of children in a family and length of stay in the hospital in either group.

DISCUSSION

A number of limitations of this study have been identified that disease has a seasonal predilection, the time available to collect the data was limited. Also, the study was conducted in a turbulent hospital environment, which was very

noisy due to constructing new building behind the pediatric ward and no limitation of visiting. In order to avoid data contamination, participants could not be randomly divided to two groups. Moreover, the two studied groups were not equivalent on all relevant factors. Between and within the groups, there were variables which could not be controlled in this study. However, despite the limitations of this study, a number of themes emerged from the findings. All parents who only received routine discharge teaching (control group) scored low; some tallied zero in categories of knowledge related to the course of the disease, side-effects of medicine and immunization of children. The routine discharge teaching only provided general information, did not provide sufficient information for parents. These parents did not know how to care for children at home, as evidenced by knowledge scores. This explains why, following discharge, a large number of telephone inquiries were previously received from parents asking about home care. Also, this ricochets to nursing literature which criticized clinical practice of discharge as not providing sufficient information to parents prior to discharge [14,22].

Here only the information provider was related to knowledge scores of parents. The findings could be limited due to small sample size. In general, parents of different age, gender, education level, number of children, as well as those with children hospitalized for varying periods and those information providers, should differ in their knowledge scores.

It is important to provide discharge teaching to parents according to the individual abilities for learning. Some young parents who are less schooling must be taught in simple terms using plain language. Also, the number of children in a

family influences learning of parents during hospitalization. Chinese mother are expected to spend more time taking care of their children than members of the family. Whereas mothers wish to spend more time with their ill children in the hospital, they also worry about their youngsters who might stay at home without proper care or supervision.

Developing a discharge plan is the linchpin of nursing; such plans take time to formulate. Length of stay in the hospital influences the amount of discharge preparation. With the routine instruction, discharge teaching about the management of this complicated disease and its home care for parents during a short length of stay in the hospital, was obviously a challenge for nurses. Parents given scant information on KD had less opportunity to ask questions about home care for their children and disease management. They were not inculcated with required knowledge about disease management and home care: physical care and psychological support for their children. Also, parents might have different difficulties in learning due to individual ability or family problems. However, the health promotion program does cater to these needs and abilities for learning. For boosting parental knowledge and increasing retention, the program imparted some written information to parents in an organized manner and in plain language. Besides that, when parents were interviewed with questionnaires individually, they were allowed to discuss their problems.

Of the 34 parents enrolled in this study, only one indicated receiving most of the information from nurses. Another 13 reported they received most information from doctors. Parents might have received information from other healthcare providers, yet they thought doctors provided most of the detailed information about their child's diagnosis and treatment. Details about diagnosis and treatment might be thought as critical instruction for parents. Hence doctors were recognized as providing most

information to parents, the finding consistent with a traditional perspective, which supposes the physician is a unique source of information [7]. According to Terry et al study, the majority of parents identified doctors as most likely to meet their needs for information, with nurses most likely to meet needs of children for physical care and psychological support [23].

During hospitalization, parents might not place knowledge of home care and long-term management of disease on an equal footing with information about diagnosis and treatment. It directly influences motivation of parent's learning. In addition, as Scott et al study found, nurses often provide information to parents during admission or clinical procedures, when parents often feel stress and have difficulty in learning; therefore parents often do not absorb and what they have been told [22,24]. Parents were present when nurses spend most of their time caring for the children, yet the control group felt that they received insufficient information from nurses.

Findings of this study show that whereas knowledge of parents who received information from the researcher outscored that of parents instructed by nurses or doctors, there is no big difference between those who gleaned information from nurses as opposed to doctors. Also, the control group felt information they received was insufficient, reporting they felt diffident in providing care for their children at home. On the other hand, having been provided with the health promotion program, the majority in the experimental group felt the information they received during hospitalization was sufficient; they felt ready to go home and care for their children. They were also amenable to regular follow-up for long-term management of the disease. This has implications for the role of pediatric nurses in providing quality care to children and their families, plus the recognition of the importance of clinical discharge teaching, which must be improved by applying strategies

like the special health promotion program.

The goal of this study was to determine whether a special health promotion program had any significant effect on knowledge scores of parents. The intent was not merely to assess the knowledge of parents, but to seek an effective method to improve their knowledge level as it applied to home care for victims of KD. Significant difference in knowledge scores cannot be explained by parent's age, gender, education level, number of children in a family and hospitalization time in either group. No subtle difference between variables could be detected between and within groups due to some variables could not be controlled; the child experiencing other infections or family problems. Besides, completed questionnaires depend on participants' interpreting questions in the same way as the researcher. Some open-ended questions were either incompletely answered or entirely omitted. The research is thus essentially a pilot study to test questionnaire design; findings are limited in application. It might be only generalized to the population from which the sample was selected. The results should be subjected to more rigorous scrutiny, such as retest of said knowledge before a firm conclusion is made. Further research is warranted to determine nurses' knowledge of KD and regarding parents' retention of the discharge teaching, parents' attitude and behavior.

Knowledge gained from this study has uncovered benefits to nursing practice: presenting the research program on clinical practice, introducing a special health promotion program and developing a model for assessing parents' knowledge for pediatric nurses. This study created an acceptable and useful information sheet and discharge teaching model for pediatric nurses in clinical practice, simultaneously revealing insight for nursing professionals who commit themselves to a path of recognizing the role of nursing intervention and taking responsibility for parental education.

Through the special health promotion

program, nurses can provide holistic care services to children's families and support nursing research endeavors in pediatric nursing. To deliver quality pediatric nursing, nurses should consider needs of parents during discharge teaching. Parental knowledge of this disease is under-researched has the potential to decrease morbidity of KD and achieve improved quality of life for the children and their families.

The timing of information for parents of children with KD is crucial and should be presented in an organized manner that parents can understand prior to discharge. Applying a simple assessment of parents' knowledge by using questionnaires enables pediatric nurses to ensure whether parents grasp required knowledge without risking unnecessary complications and without increasing the workload of nursing staff.

The study thus revealed an appreciable amount about parents' learning, while at the same time creating an acceptable and useful information sheet and discharge teaching model for nurses in the rapidly changing clinical milieu. The nursing staff has gained insight into the path of nurses recognizing the role of nursing intervention and seeking to take the responsibility for parental education. Only when clinical nurses realize parents' views and those changes required, will true quality care be achieved in pediatric nursing.

REFERENCES

1. American Heart Association Committee on Rheumatic Fever, Endocarditis, and Kawasaki Disease. Diagnostic guidelines for Kawasaki disease. *AJDC* 1990;144:1218-9.
2. Chang JS, Lin JS, Peng CT, et al. Kawasaki disease complicated by peripheral gangrene. *Pediatr Cardiol* 1999;20:139-42.
3. Castiglia PT. Growth and development--Kawasaki disease. *J Pediatric Health* 1996;10:124-6.
4. Chang JS, Tsai CH. The risk of factors of coronary arterial aneurysm in Kawasaki disease. *China Medical College Journal* 1994;3:109-16.
5. Rubin B, Cotton D. Kawasaki disease: a dangerous

- acute childhood illness. [Review] *Nurse Pract* 1998; 23:34-48.
6. Dimakakos P, Bredakis J, Papageorgiou A, et al. A case of relapsing Kawasaki disease and review of the literature. [Review] *Vasa* 1996;25:317-26.
 7. Scott LD. Perceived needs of parents of critically ill children. *J Soc Pediatr Nurs* 1998;3:4-12.
 8. Baker A. Acquired heart disease in infants and children. *Crit Care Nurs Clin North Am* 1994;6:175-86.
 9. Dhillon R, Clarkson P, Donald AE, et al. Endothelial dysfunction late after Kawasaki disease. *Circulation* 1996;94:2103-6.
 10. Lynch MH, Gray JL. Kawasaki disease--would you know it if you saw it? And--what would you do about it? *Pediatr Nurs* 1982;8:96-101.
 11. Wong DL. Whaley & Wong's Nursing Care of Infants and Children. 5th ed. St. Louis: Mosby, 1995.
 12. Payling KJ. Kawasaki disease. [Review] *Prof Nurse* 1997;13:108-9.
 13. Ball M, Glasper A, Yerrell P. How well do we perform? Parents' perceptions of paediatric care. *Prof Nurse* 1998;4:115-8.
 14. Bradley R, Singer J. Support and information for parents. *Paediatric Nursing* 1991;3:18-20.
 15. Bailey R, Caldwell C. Preparing parents for going home. *Paediatric Nursing* 1997;9:15-7.
 16. Lux KM. New hope for children with Kawasaki disease. *J Pediatr Nurs* 1991;6:159-65.
 17. McEnhill M, Vitale K. Kawasaki disease: new challenges in care. *MCN Am J Matern Child Nurs* 1989;14:406-10.
 18. Medicus L. Kawasaki disease: what is this puzzling childhood illness? [Review] *Heart Lung* 1987;16:55-60.
 19. Polgar S, Thomas S. Introduction to Research in the Health Science. Melbourne: Churchill Livingstone, 1996.
 20. Hildebrand DK. Statistical Thinking for Behavioral Scientists. Boston: Duxbury Press, 1986.
 21. Munro BH. Statistical Methods for Health Care Research. Philadelphia: JB. Lippincott, 1997:111.
 22. Shreve B. Kawasaki disease: early treatment/positive results--one family's story. *Pediatr Nurs* 1993;19:607-10.
 23. Terry DG. The needs of parents of hospitalized children. *Child Health Care* 1987;16:18-20.
 24. L'Orange C, Werner-McCullough M. Kawasaki disease: a new threat to children. *Am J Nurs* 1983; 83:558-62.

川崎氏症照護衛教對病童父母居家照護知識之影響

蘇家嫻 張鳳媛 彭慶添¹ 蔡長海¹ 張正成¹

中國醫藥大學附設醫院 護理部 兒科部¹

目的 兒童罹患川崎氏症易引發冠狀動脈血管病變，甚至造成突然死亡。護理衛教可以提高父母相關知識以減少合併症之發生。本研究目的在探討川崎氏症兒童照護衛教對提高父母的居家照護知識的影響。

方法 研究設計以結構式問卷調查方式進行問卷訪談。於中部某醫學中心小兒科病房中，以立意取樣，控制組14位，僅接受病房例行出院衛教。實驗組20位，除接受病房例行出院衛教，並給予川崎氏症照護衛教。所得資料以SPSS Package for Windows 9.0分析，採敘述性統計、Mann-Whitney U test進行分析。

結果 研究結果顯示川崎氏症照護衛教能明顯提升父母對病童的居家照護之相關知識 ($p < 0.001$)。

結論 期望本研究初步結果能提供臨床川崎氏症照護衛教及出院照護標準之制定，增加病童父母的知識，減少病童與家庭之因疾病而造成的損傷。(中台灣醫誌 2006;11:73-81)

關鍵詞

出院衛教，川崎氏症，知識

聯絡作者：張正成

地址：404台中市北區育德路2號

中國醫藥大學附設醫院 兒科部

收文日期：2005年1月26日 修改日期：2005年6月14日

接受日期：2006年4月20日