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MANAGEMENT BEHAVIOUR OF CAREGIVERS FOLLOWING PAEDIATRIC ASTHMA EDUCATION PROGRAMME (PAEP)

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ABSTRACT

Background: The prevalence of asthma among children is common. In Malaysia, the clinical observations have demonstrated that many children with asthma were not properly assessed and did not get proper treatment. Hence, poor asthma control could cause disruption to the child's ability to get enough sleep, to pay attention, to participate in school activities and thus affecting their quality of life.

Aim: The objective was to determine the effect of PAEP to change the quality of life of children, parents' management practice and parents' technique of using an inhaler for their asthmatic children.

Methods: The study design was a one group pre-test-post-test intervention study. The respondents consisted of 78 parents with asthmatic children, aged between 8 to12 years old. Parents were required to answer the Paediatric Quality of Life Inventory Questionnaire, Management Behaviour Survey for Familial Caregivers and skills of inhaler technique using the checklist at the Paediatric Clinic Hospital USM. Following that were given a date to attend PAEP and were assessed two months later for post-intervention. The analysis for PedsQL, Management Behaviour Survey for Familial Caregivers and skill of inhaler technique was done by using paired *t*-test. A total of 70 parents completed the study.

Results: The study showed that the mean age for children with asthma was 9.31 years. PedsQL pre-intervention scores were 75.8%, and post-intervention 82.8%. The Mean of Management Behaviour Survey for Familial Caregivers scores increased from 53.16 to 62.33 pre-intervention and post-intervention respectively. While the mean skill scores for inhaler user had increased from 3.43 to 7.13 for the MDI with a spacer. The findings showed statistical significance with *P*-values (<0.001) for PedsQL, Management Behaviour Survey for Familial Caregivers and skill scores for inhaler use.

Conclusion: The PAEP had improved the children's quality of life, parents management practice and inhaler skills among parents with asthmatic children.

Keywords : Prevalence, asthma, quality of life

INTRODUCTION

Asthma is a chronic inflammatory syndrome that affects children over the world. It is a heterogeneous condition characterized by persistent symptoms such as dyspnea, chest tightness, wheezing and cough that can lead to airway obstruction, which is either partially or completely reversible using bronchodilator (Ball, 2003).

Consistent management of asthma at home is necessary to achieve control. This includes the ability to identify early signs and symptoms of an asthma attack and administer the metered dose inhaler correctly. It is vital for family members to equip themselves with correct knowledge on asthma. Asthmatic children experience functional impairments such as impaired physical activity, school functioning and avoidance of social activities. Hence, good caregiver management behaviour is vital for a better care and quality of life. Caregiver management behaviour plays an important part in asthma management. Their practice at home can improve their child health status. Asthma management depends on the parents until the child can manage on

their own.

Studies have shown that the majority of parents have a limited understanding of their asthmatic children (Conway, *et al*., 1999; Fadzil, A., *et al*., 2002 & Norzila, M. Z., *et al*., 2000). Some parents have adequate knowledge on the causes and symptoms of asthma but are less informed about the management of asthma (Bahari *et al*., 2005). The majority of parents get to know about asthma through their family members who are suffering from asthma or after seeing someone having an asthmatic attack (Bahari, 2005). Al Binali *et al*., (2010) identified that older mothers were more knowledgeable than the younger mothers. Jalaludin *et al.*, (2002) showed that a total of 70.6% of families of children with asthma in Kuala Lumpur and 76.3% in Terengganu used carpet in the house. Nookong, *et al.,* (2005) found that caregivers tend to pay attention to avoid allergic triggers inside and outside the home more than paying attention to the general environmental control

Short education program improve knowledge and skill but some skills need more emphasizing and training (Aziz *et al.,*2006). Training on identifying asthma triggers, recognizing early warnings signs, and correct technique of metered dose inhaler use are important to achieve a better quality of life. Asthma is related to the significant impact on the quality of life of the children with asthma and their caregivers (Juniper *et al*., 1997). The aim of this study is to determine the effect of a newly developed Paediatrics Asthma Education Programme (PAEP) on parents' management behaviour in children with asthma.

METHODOLOGY

Study Design and Participants

This study utilized a pre-post single group study design to investigate the effect of PAEP on the caregiver management behaviour. Parents of children aged 8 to 12 years old with asthma who had been under follow-up at the paediatric clinic of Hospital Universiti Sains Malaysia was identified. A total of 78 parents were enrolled in the study. The inclusion criteria were: (1) Parents of asthmatic children of age between 8 to12 years old (2) Each child had been on at least one health care visit for asthma in the preceding year (3) Each child had been prescribed medication for asthma on a daily basis (4) The parents had to be contactable by phone (5) The primary caregiver speaks Malay language. On the other hand, the exclusion criteria were: (1) The child had other health problems (heart diseases, cancer, diabetic or other chronic condition) (2) The parents refused to participate or not consented.

Paediatrics Asthma Education Programme (PAEP)

PAEP is a programme delivered to parents through conventional lecture and brochures. Patients' education is considered an essential component of asthma prevention and control. The development of PAEP was based on the guideline from Academy of Medicine of Malaysia *et al*. (2015). This programme takes two hours to complete and is delivered via lecture and clinical demonstrations. Attractive graphics and a suitable combination of colours are used to stimulate their interest, supported by two brochures (asthma action plan and how to use an inhaler) that are designed to enhance their understanding and memory after the programme.

This programme emphasizes the importance of practical demonstrations, covering the concept of asthma as an inflammatory disease, symptoms and signs of asthma attacks, trigger factors and how to identify them, the concept of two classes of medication i.e. reliever and prophylaxis medication, the recognition of acute attacks, the asthma action plan and the demonstrations on inhaler techniques. PAEP also includes a small group discussion among parents (a maximum of 20 parents per group) to allow sharing of experience and feedbacks on inhaler techniques and exchanging ideas on managing an asthmatic child during the session.

Measurement Tool

This study used a self-administered questionnaire set, consisting of two main parts. Part 1 consists of questions on socio-demographic information of the child and the parents. Part 2 assesses the caregiver management behaviour using the Malay version of Management Behaviour Survey for Familial Caregivers (MBSFC-M) questionnaire, which was adapted from Management Behaviour Survey for Familial Caregivers (MBSFC) (10). The original questionnaire has 20 items, using a five-point Likert-type scale ranging from 1-5 (1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = always) and an option to

indicate the item is not applicable (8 = does not apply). The questions are divided into three sections, namely prevention/adherence to treatment (12 questions), assessment and monitoring (four questions) and exacerbation-intervention strategies (four questions). The higher score (closer to 5) indicates better management behaviour of asthma. The reported internal consistency reliability of the original MBSFC was Cronbach's alpha = 0.73.

The details of the translation and validation processes of MBSFC-M are reported elsewhere. During the translation process, MBSFC-M underwent forward-backward translation procedure, expert panel review, and field pre-test to come up with a preliminary version of the questionnaire. This was followed by a validation study among a sample of 37 parents of asthmatic children, which resulted in the localized questionnaire consisting of 15 items for the three sections: prevention/adherence to treatment (eight items); assessment and monitoring (three items) and exacerbation-intervention strategies (four items). Five items were deleted in the Malay version as the items were not applicable locally. The internal consistency reliability of MBSFC-M was Cronbach's alpha = 0.83.

Procedures

In the pre-intervention phase, the recruited parents were asked to complete the questionnaire set. The parents were then scheduled to attend PAEP on the agreed dates. PAEP was conducted by a trained nurse educator. In the post-intervention phase eight weeks after PAEP, the questionnaire set was mailed to the parents. Completed questionnaires were then returned to the researchers by self-addressed stamped envelopes.

Statistical Analysis

The data entry and analysis were done using IBM SPSS Statistics version 20. The data were analyzed by paired *t*-test.

Ethical Approval

The Research Ethics Committee (Human), Universiti Sains Malaysia approved the study protocol (reference number: USM/JEPeM/140381). Permission to translate and adapt MBSFC was obtained from the author (Nookong, 2005).

RESULTS

The socio-demographic information of the parents is presented in Table 1. Most parents were female (n = 63, 80.8%), Malay (n = 76, 97.4%) and coming from low income family (n = 56, 71.8). Over half of the family members were smokers (n = 40, 51.3%). Most of the parents (n = 56, 71.8%) also reported the history of asthma among the family members.

Table 1. Frequency distribution of parent's characteristics (n=78)

Parent's characteristics	n (%)
Gender	
Female	63 (80.8)
Male	15 (19.2)
Age (years)	39.7 (6.90)[a]
Ethnicity	
Malay	76(97.4)
India	1(1.3)
Chinese	1(1.3)
Education level	
Primary school	5 (6.4)
Secondary school	52 (66.7)
College / university	21 (26.9)
Monthly income	
Low income	56 (71.8)
Moderate income	11 (14.1)
High income	11 (14.1)
Family members who are smoker	
Yes	40 (51.3)
No	38 (48.7)
History of asthma	
Yes	56 (71.8)
No	22 (28.2)

[a]*Mean (SD)*

Table 2 shows the comparison of mean MBSFC-M scores of the parents at pre-intervention and eight weeks post PAEP. There was a statistically significant increase in the MBSFC-M scores from pre-intervention (Mean=53.16, SD=10.22) to post-intervention (Mean=62.33, SD =7.26), an increase by 9.16 score. This indicates the positive effect of PAEP on the caregiver management behaviour.

Table 2. Comparison of the mean scores of MBSFC-M pre and post PAEP (n = 65)

Variables	Mean (SD)		Mean diff (95% CI)	*t*-stat (df)	*P*-value[a]
	Pre	Post(2 months)			
MBSFC-M total score	53.16 (10.22)	62.33 (7.26)	9.16 (7.27, 11.06)	64	0.001

[a]*paired t-test*

DISCUSSION

The improvement of the caregiver management behaviour as indicated by an increase in MBSFC-M score shows the positive effect of PAEP on the caregivers. There may be several reasons for this situation. The delivery of PAEP education interactively and the practical demonstrations on the inhaler techniques could be the reasons. Next, the conventional lecture was included as one of the delivery tools in the programme to promote a better understanding about asthma among the parents. Additionally, the brochures with attractive graphics and a suitable combination of colours were also used to ensure sustainability of the programme.

In comparison, Celano *et al.,* (2012) reported similar improvement in parental asthma management after participation in an asthma health education programme. Previous studies have shown that the use of short education programme for parents was able to improve their inhaler technique with a spacer (Aziz *et al.,* 2006). A combination of written and verbal instruction showed most of the patients was able to achieve the maximum score for inhaler technique with Turbuhaler (Vichyanond *et al.,* 1994).

The use of brochures as printed education materials is more efficient than spoken language as the reader can control the speed at which they read and understand the information (Redman *et al*., 2007). Other than that, written education tools are economical which can strengthen verbal command and are the most preferred educational ways by clients (Rankin *et al*., 2005). Mayer *et al*., (2009) put forth that, it is better to have two or three brochures that are easy to understand, as compared to a brochure that covers everything but may cause an information overload. Based on this suggestion, PAEP utilized two brochures on the asthma action plan and the use of an inhaler.

According Clayton (2009) graphics can be used to narrow the language barriers, reducing the amount of text to read, stressing key information and providing step by step instruction. Graphics presented should be simple, realistic, and relevant with a focus on parents' actions. Pictorial usage in health education has been also shown to increase attention, comprehension, recall of what was explained and adherence to health standards with quick recall of the recommendations (Houts *et al*., 2006). Mayer and Villaire (2009) said that illustrations were used to support, improve, and clarify the written word.

Asthma education does not include asthma knowledge acquisition but the ability to sustain the knowledge gained, that can result in an effective everyday application of the acquired knowledge (Bryant-stephens & Li, 2004). Therefore, health information delivered must be accurate, relevant to the target population and based on current practice standards (Clayton, 2009). Overall, the information presented were based on what have been suggested by the asthma education plan including the meaning of asthma signs and symptoms of asthma attacks, trigger factors and identification of asthma, medications of the same, recognition of acute attacks and asthma action plan, and lastly demonstration on inhaler technique. Bryan Stephens and Li, (2004) stressed that, when the learners have obtained the knowledge, they can retain most of the knowledge acquired up to one-year post command.

The other education programmes are different from PAEP, which mainly focused in the clinic or outpatient setting. PAEP module is delivered by a nurse educator using similar dialect and level of understanding for the parents. The idea of health care promotion and education should be taught by a person who lives within the same society and has experienced the same environmental and social pressure (Bryant-Stephens & Li,2004). PAEP also focuses on educating a small number of parents in each setup. This allows parents to give more attention to learning. Asthma education, particularly within a small group with an interactive format, had improved overall care for asthmatic children (Watson *et al*., 2009).

According to our knowledge, this is the first reported study in Malaysia to assess parents' management behaviour at home for children with asthma. Correct asthma management behaviour is crucial for the family to live a normal life. Identified trigger factors for asthma attack should be informed and preventive measures and steps should be taken to avoid an acute attack. Knowledge without practice on the right management at home is deemed a failure for better livelihood. The effective of asthma control largely depends on families' attitude towards managing environmental factors and lifestyle (El-Sharif *et al*., 2003).

There were a few identified limitations of the study. The study location was in the state of Kelantan, which has a generally homogenous population, mostly of Malay ethnicity. In comparison, Malaysia is a multiracial country, thus Kelantan may not be representative of Malaysia, consequently limiting the generalizability of this study findings. Next, this study also did not include a control group. This was because the primary goal of PAEP is to educate parents about asthma, thus the researchers considered the inclusion of control group to be unethical in the present study as it may marginalize the control group in term of knowledge and possible benefits of the programme. As such, the present study is limited in term of controlling for effects that might be expected over the period of eight weeks without intervention. Additionally, recruitment of the students seemed to be a problem due to reduced number of children in the school-aged group due to better control of symptoms prior to the recruitment process. Most of the children had three or six-month appointment. There was time frame difficulty for long-term assessment following completion of PAEP. This is to be investigated but however, the availability of take-home brochure may be useful factors in influencing memory retention.

CONCLUSION

In the present study, PAEP showed a positive effect on the caregiver management behaviour among the parents of asthmatic children in Kelantan as indicated by the significant increase in MBSFC-M scores following the programme. Acknowledging the limitations of the study, more studies are required to learn the applicability of PAEP in other states in Malaysia. Future research may also focus on long-term assessment of PAEP for retention of the information, practice, and motivation to maintain a consistent asthma control at home.

PAEP has given some insight on changes required for the parental education trend. The nursing curriculum may need to focus on the importance of health education among parents in controlling asthma among the children. This allows parents to take an active role in the management of asthma.

REFERENCES

Academy of Medicine of Malaysia, Malaysian Thoracic Society, & Lung Foundation of Malaysia. (2014). *Clinical Practice Guideline for the Management of Childhood Asthma.*

Al-Binali, A.M., Mahfouz, A.A., Al-Fifi, S., Naser, S.M. and Al-Gelban, K.S., 2010. Asthma knowledge and behaviours among mothers of asthmatic children in Aseer, south-west Saudi Arabia. *Eastern Mediterranean Health Journal*. 16(11), pp 1153.

Aziz, N.A., Norzila, M.Z., Hamid, M.Z. & Noorlaili, M.T. (2006). Skills amongst parents of children with asthma: a pilot interventional study in primary care setting. *The Medical journal of Malaysia.* 61(5), pp 534-539.

Bahari, M.B., Mat, N.M.N., Nurrochmad, A., Yayoi, K., Masahiko, O., Yajima, Y., Narita, M., Nagase, H., Suzuki, T., Ahmad, N. & Ismail, S. (2005). Parental knowledge on childhood asthma in an outpatient setting. *Malaysian Journal of Pharmaceutical Sciences*. 3(1), pp 1-10.

Ball, J. & Bindler, R. M. (2003). *Pediatric Nursing: Caring for Children* (3rd ed.). New Jersey: Prentice Hall.

Bryant-Stephens, T. & Li, Y. (2004). Community asthma education program for parents of urban asthmatic children. *Journal of the National Medical Association.* 96(7), pp 954.

Celano, M.P., Holsey, C.N. & Kobrynski, L.J. (2012). Home-based family intervention for low-income children with asthma: a randomized controlled pilot study. *Journal of Family Psychology* 26(2), pp 171-178.

Clayton, L.H. (2009). TEMPtEd: development and psychometric properties of a tool to evaluate material used in patient education. *Journal of advanced nursing.* 65(10), pp 2229-2238.

Conway, T., Hu, T.C., Bennett, S. & Niedos, M. (1999). A pilot study describing local residents' perceptions of

asthma and knowledge of asthma care in selected Chicago communities. *CHEST Journal*. 116(suppl_2), pp 229S-234S.

El Sharif, N., Abdeen, Z., Barghuthy, F. & Nemery, B. (2003). Familial and environmental determinants for wheezing and asthma in a case control study of school children in Palestine. *Clinical & Experimental Allergy*. 33(2), pp 176-186.

Fadzil, A. & Norzila, M.Z. (2002). Parental asthma knowledge. *The Medical Journal of Malaysia.* 57(4), pp 474-481.

Houts, P.S., Doak, C.C., Doak, L.G. & Loscalzo, M.J. (2006). The role of pictures in improving health communication: a review of research on attention, comprehension, recall, and adherence. *Patient education and counseling*. 61(2), pp 173-190.

Jalaludin, J., Hashim, Z., Taib, N.M., Lubis, S.H. & Hashim, J.H. (2002). Perbandingan pengaruh persekitaran kediaman terhadap serangan asma di antara kanak-kanak Kuala Lumpur dengan Terengganu, Malaysia. *Jurnal Kesihatan Masyarakat.* 8(1), pp 51-62.

Juniper, E.F. (1997). How important is quality of life in pediatric asthma?. *Pediatric Pulmonology.* 24(S15), pp 17-21.

Mayer, G. and Villaire, M. (2009). Enhancing written communications to address health literacy. *OJIN: The Online Journal of Issues in Nursing.* 14(3).

Nookong, A. (2005). *Familial caregivers' management behaviors and quality of life for children with asthma. Iowa: University of Iowa.*

Norzila, M.Z., Hasanah, I., Deng, C.T. & Azizi, B.H. (2000). Asthma education: how much does it improve knowledge of childhood asthma amongst medical students and paramedics?. *The Medical journal of Malaysia.* 55(3), pp 324-330.

Rankin, S.H., Stallings, K.D. and London, F., 2005. Patient education in health and illness. *Lippincott Williams & Wilkins.*

Redman, B.K. (2007). The practice of patient education: A case study approach. *Elsevier Health Sciences.*

Vichyanond, P., Phanichyakarn, P., Omar, A.H., Tam, A. & Wong, E. (1994). Ease of handling and efficacy of Bricanyl Turbuhaler in *Asian asthmatic children. Asian Pacific Journal of Allergy and Immunology.* 12(1), pp 1-6

Watson, W.T., Gillespie, C., Thomas, N., Filuk, S.E., McColm, J., Piwniuk, M.P. & Becker, A.B. (2009). Small-group, interactive education and the effect on asthma control by children and their families. *Canadian Medical Association Journal.* 181(5), pp 257-263.