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Wybrane aspekty jakości życia rodziców dzieci chorych na astmę oskrzelową

Streszczenie

Wstęp. Astma oskrzelowa jest najczęstszą choroba przewlekłą wieku dziecięcego, a liczba zachorowań na nią ciągle wzrasta. W świetle współczesnej wiedzy astma wymaga kompleksowego leczenia i zaangażowania rodziny dziecka w długotrwały proces terapeutyczny i edukacyjny. Wszystkie obciążenia wynikające z przewlekłej choroby dziecka i jej leczenia mogą zaburzać funkcjonowanie całej rodziny.

Cel pracy. Celem pracy była ocena jakości życia rodziców dzieci chorych na astmę oskrzelową.

Materiał i metody. Badaniami objęto 100 rodziców dzieci chorych na przewlekłą astmę oskrzelową, leczonych w Poradniach Pulmonologicznych DSK w Lublinie. Jako narzędzie badawcze wykorzystano kwestionariusz PACQLQ, kwestionariusz ankiety opracowany dla celów pracy oraz analizę dokumentacji medycznej.

Wyniki badań. Zdaniem 90% ankietowanych rodziców choroba dziecka i jej leczenie ogranicza ich aktywność życiową. Astma dziecka zaburzała funkcjonowanie emocjonalne u 98% rodziców. Analiza statystyczna potwierdziła istotną zależność między stopniem ciężkości choroby dziecka a jakością życia rodziców (p=0,004). Ponad połowa ankietowanych rodziców (59%) zaobserwowała u dzieci niepokojące ich objawy uboczne, które kojarzyli ze stosowanym leczeniem astmy. Analiza statystyczna wykazała istotny wpływ faktu występowania ubocznych objawów terapii astmy u dziecka na jakość życia rodziców (p=0,001). W badaniach analizowano również wpływ obciążenia finansowego wynikającego z leczenia astmy oskrzelowej dziecka na jakość życia rodziców. Zastosowana analiza statystyczna wykazała istotny ujemny wpływ powyższego parametru na jakość życia rodziców (p=0,026). Przeprowadzona analiza korelacji ujawniła istotną, aczkolwiek niewielką, dodatnią korelację pomiędzy okresem leczenia dziecka przez lekarza specjalistę a jakością życia rodziców (r=0,203, p<0,05).

Wnioski. Obciążenia wynikające z przewlekłej choroby dziecka znacznie obniżają jakość życia rodziców, zwłaszcza w sferze funkcjonowania emocjonalnego. Terapię dziecka astmatycznego należy rozszerzyć o oddziaływania psychoedukacyjne w stosunku do jego rodziny.

Słowa kluczowe: astma oskrzelowa, jakość życia, rodzice.

Selected aspects of quality of life in parents of children with bronchial asthma

Summary

Introduction. Bronchial asthma is the most frequent chronic childhood disease of increasing morbidity. In the light of recent knowledge asthma requires complex treatment and involves child's family in long-term therapeutic and educational process. All burden resulting from child's chronic condition and its treatment can impair the activity of the whole family.

Aim. The purpose of study was to evaluate the quality of life of the parents whose children suffer from bronchial asthma.

Material and methods. The investigation covered 100 parents with children suffering from chronic bronchial asthma and undergoing ambulant treatment at the Pulmonological Out-patient Department, Children Clinical Hospital in Lublin. The research tools used in the study were: PAQLQ questionnaire, a questionnaire created for the purpose of study and analysis of medical records.

Results. According to 90% parents, child's disease and its treatment limit their life activity. Child's asthma was responsible for impaired emotions in 98% parents. Statistic analysis confirmed significant correlation between the degree of asthma severity and parents' QL (p=0.004). Over half of the respondents (59%) observed annoying side effects believed to be associated with the type of treatment. Statistic analysis found significant influence of side effects of the therapy on the parents' QL (p=0.001). The study also analyzed the role of financial expenses to cover the cost of BA treatment on the parents' QL. Statistic analysis revealed significant influence of the increased value of that parameter on the parents' QL (p=0.026). The analysis of correlation revealed significant, slight though, positive correlation between the duration of treatment by a specialist and parents' QL (r=0.203, p<0.05).

Conclusions. Burden due to child's chronic disease decreases considerably parents' QL, especially in the area of emotions. Therapy of asthmatic child should be extended by psycho-educational activities addressed at his/her family.

Key words: bronchial asthma, quality of life, parents.

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INTRODUCTION

Bronchial asthma (BA) is the most frequent chronic childhood disease of increasing morbidity [1, 2]. In the light of recent knowledge asthma requires complex treatment and involves child's family in long-term therapeutic and educational process. Progress of treatment depends on the parents as they are responsible for monitoring the course of asthma, fulfillment of doctor's orders since it is they who make decisions concerning appropriate pharmacotherapy in the situation of exacerbation of the symptoms [3-6]. All burden resulting from child's chronic condition and its treatment can impair the activity of the whole family.

AIM

The purpose of study was to evaluate the quality of life (QL) of the parents with children suffering from bronchial asthma.

MATERIAL AND METHODS

The investigation covered 100 parents with children suffering from chronic bronchial asthma and undergoing ambulant treatment at the Pulmonological Out-patient Department, Children Clinical Hospital in Lublin. The study used a diagnostic survey by means of a questionnaire and the analysis of medical records. Polish version of Juniper's questionnaire (PACQLQ) was used to evaluate the quality of life of the parents with children suffering from BA. Another investigation tool, a questionnaire constructed for the purpose of study was used to obtain socio-demographic data concerning the parents and child's disease. Besides, ambulant treatment charts filed at the outpatient department were analyzed too. The results were statistically assessed with SSPC 8.0. Significant differences between the parameters were determined by tests of variance analysis, multiple comparison by Dunett T3 and t-Student, dependences were determined by rSpearman coefficient of rank correlation, $p<0.05$ assumed significant.

RESULTS

The group of respondents consisted of 85 mothers and 15 fathers, mean age 40.1±6.4 years, 47% lived in town and 53% in the country. A considerable part of the examined (87%) were in formal marriages. The examined had 1 to 6 children. The majority of parents (56%) had secondary education. Almost half of them (49%) were occupationally active. The others (51%) did not earn their living. Subjective evaluation of economic situation found that 68% were on the sufficient level and 66% reported good living conditions. The children with chronic BA were 8–17 years old (mean age 12.3±2.6 years). The children had suffered from BA for 8.0±3.6 years (1 year–17 years). Chronic moderate asthma was detected in 51% children, chronic mild asthma in 45% and 4% cases were chronic severe form. PACQLQ is composed of 13 questions grouped into two subscales: "activity" and "emotions". The score of each subscale and total score (global QL) can range 1–7 points: 1 means the lowest QL and 7 the highest. Global index of QL in the group of parents examined was x=4.33±1.29 (1.7–7.0). Only 2 parents out of 100 examined, assessed their QL as the highest (7 points). According to 90% parents, child's disease and its treatment limit their life activity. The score of the „activity" subscale was x=4.68±1.45 (1.8–7.0). Child's asthma was responsible for impaired emotions in 98% parents. The subscale of „emotions" score was x=4.18±1.32 (1.3–7.0). The analysis of the influence of socio-demographic variables on QL of the parents examined revealed that neither sex, age nor characteristics of the family differentiated their QL. Statistical analysis confirmed significant differences in mean QL estimates depending on the parents' education, occupational activity and sick child's age (Table 1 and 2). The assumption was that the degree of asthma severity could affect the parents` QL estimates. Statistic analysis (Table 1) confirmed significant correlation between the degree of asthma severity and parents' QL. Another parameter analyzed was the influence of the type of BA treatment on parents' QL. The biggest group of children were on conventional treatment (72%) following GINA guide, 18% sick children underwent

TABLE 1. Parents' QL depending on selected parameters.

Independent variable	Parents' global QL		
	X	SD	P
Degree if asthma severity			0.004**
light	4.60	1.27	
moderate	4.28	1.31	
severe	3.17	0.43	
Method of treatment			0.009**
improperly treated	3.41	0.94	
traditional	4.33	1.26	
modern	4.85	1.36	
Side effects of treatment			0.001*
present	3.94	1.24	
absent	4.89	1.15	
Emergency medical			
intervention required			0.021*
yes	4.17	1.27	
no	4.87	1.23	
Burden for family budget			0.026*
considerable	4.18	1.23	
little	4.87	1.40	
Carer's occupational activity			0.029*
works	4.53	1.40	
does not work	4.15	1.16	
Carer's education			0.030***
elementary	3.82	1.20	
vocational	4.20	1.42	
secondary	4.31	1.17	
higher	5.38	1.47	

* t-Student test
** Dunett T3 test
*** variance analysis

TABLE 2 Correlation between selected parameters and parents' QL.

Independent Variable	Activity	Emotions	Global QL
Treatment method	0.193	0.289*	0.264*
Duration of treatment by specialist	0.168	0.207*	0.203*
Duration of treatment by G.P.	-0.267**	-0.268**	-0.277**
FEV1 % predicted value	0.167	0.242*	0.226*
Number of factors causing exacerbation	-0.476**	-0.364**	-0.428**
Emergency medical intervention requirement	-0.347**	-0.313**	-0.341**
School absence	-0.322*	-0.285*	-0.295*
Carer's education	0.216*	0.240*	0.238*
Child's age	0.260*	0.109	0.175

* – $p<0.05$
** – $p<0.001$

modern therapy following GOAL [2,7]. The latter form of therapy tells to administer inhaled glicocorticosteroids (iGS) with long-activity β2 mimetics (administered in one inhalator) in each form of asthma [7]. However every tenth child (10%) was treated improperly, i.e. the treatment failed the standards of GINA or GOAL. Statistic analysis (Tables 1 and 2) confirmed significant influence of the treatment regimen on the parents' QL. Over half of the respondents (59%) observed annoying side effects believed to be associated with the type of treatment. Parents reported side effects of iGS mainly such as oral mycosis, hoarseness and sore throat. They also mentioned systemic side effects associated with other antiasthmatic drugs (e.g. nausea, vomiting, stomachache, muscular tremor, anxiety and weakened concentration). Statistic analysis (Table 1) found significant influence of side effects of the therapy on the parents' QL. The study also analyzed the role of financial expenses to cover the cost of BA treatment on the parents' QL. The biggest percentage of parents (78%) admitted it is a considerable financial burden, others (22%) thought it is little. Statistic analysis (Table 1) revealed significant influence of the increased value of that parameter on the parents' QL. The study also tried to establish the correlation between the duration of specialist treatment (by pulmonologist, allergologist) and the parents' QL and correlation between the duration of treatment by G.P. and the parents' QL. The analysis of correlation (Table 2) revealed significant, slight though, positive correlation between the duration of treatment by a specialist and parents' QL. Besides, little, weak though, negative correlation was revealed between the duration of treatment by G.P. and the parents' QL. Other parameter tested concerned the effects of the number of factors responsible for the exacerbation of asthma symptoms and the parents' QL. The analysis of correlation (Table 2) found significantly negative correlation. The evaluation of another negative factor likely to influence QL found that within the last year big percentage of children (77%) required additional treatment for the exacerbation of symptoms. The analysis of correlation (Tables 1 and 2) found significantly negative correlation between the frequency of emergency ambulant treatment and the parents' QL. The study also analyzed the frequency of school absence over the last year as a result of exacerbated symptoms of asthma. Marked majority of children (87%) were absent from school. The analysis of correlation (Table 2) confirmed significantly negative correlation between the frequency of child's absence from school and parents' QL. The analysis of correlation (Table 2) found significant positive dependence between the child's respiratory parameters and parents' QL.

DISCUSSION

Many articles underline the dysfunction of the family with asthmatic child [4, 5, 8-11]. Our investigation on the parents' QL revealed mean estimates which confirms impaired functions of the family due to child's illness. Our results found that child's BA is the source of emotional burden for the parents, fear, anxiety and feeling of helplessness. Analogical results were obtained by other authors (Lohn, Pilecka) who studied emotions of the parents whose children suffered from BA [12,13]. Pilecka observed the occurrence of unpleasant experience and tense family atmosphere due to continuous fear concerning their children's health condition and difficulties at school [13]. It is an unfavorable situation as Dyga-Konarska writes: "parental anxiety increases child's fear and can provoke subsequent attacks of asthma" [14]. The analysis of our results confirmed that child's BA alters the organization of the family life, limits parents' activity, which pertained to the younger children; it may suggest that parents adapt to the situation of their child's illness. Other articles also present similar results. Kluger, among others, observed that all the family of the asthmatic child reported social activity lower than typical of the child's age and socio-economical status, which may affect the model of communication among the family members [op cit. 15]. Lohn examined the family situation of asthmatic children and found that unfavorable economic situation perceived by the parents, living in the country and single-parent family is paired with emotional burden as a result of experiencing child's illness [12]. Our investigation found no such correlation which is similar to the results of Swedish studies [10]. Worse score of the emotional subscale in comparison to the subscale of limited activity can be accounted for by anxiety caused by the attacks of asthma the child has. Analogically to Lohn we observed correlation between the parents' QL and their education and occupational activity [12]. We obtained significantly lower estimates of QL among the unemployed parents with lower lever of education in comparison to others. The level of parents' education can influence employment opportunities, thus influence the economic status of the family. Unemployment among the parents has disadvantageous effects on the financial income of the family. Low income is stressful and decreases QL [15,16]. Lala et al. state that burden on the family whose child suffers from BA understood as the influence of disease on the lifestyle and health of other family members is significantly associated with the degree of asthma severity [15]. We observed that QL of the parents decreases with the degree of asthma severity, which seems logical. However modern methods of treatment enable good monitoring even in severe forms of asthma. Reichenberg, and Broberg and Juniper obtained similar results [8, 10]. BA can be successfully treated and its adverse influence on the life of the

family of the sick child can be reduced [7,17,18]. In our investigations the respondents evaluated their QL significantly higher when modern treatment was applied in comparison to other methods. Mahajan and Osman observed higher QL among the parents whose children were treated by iGS in comparison to other drugs, mainly due to fewer incidents of child's awakening at night caused by asthma [9,18]. Also Reichenberg and Sawyer noted higher QL of the parents whose children received iGS treatment in comparison to other medicines which produced increased safety and better mood of the parents due to „good" treatment of their child [10,11]. Proper management of asthma positively influences QL of both sick children and their parents. On the other hand the occurrence of side effects of the therapy can possibly influence QL [17]. Our study found that the presence of side effects of the treatment significantly lowered patents' QL as it was the cause of additional worry and necessity to counteract the complications. Many researchers state that the investigations of QL contrary to other methods testing the efficiency of treatment include the assessment of side effects of the therapy [8-11,18]. Each chronic disease also involves the economic aspects of the treatment since long-term therapy is expensive [4-6, 17]. Expenses to cover the costs of medicines can consume a considerable part of the family income [4,6]. In the USA the estimated cost can be 5.5–14% total family income [2]. In Germany it can amount up to € 8,000 per year [2]. Our study found a significant correlation between financial burden due to the treatment of child's asthma and parents' QL, which seems evident. Storms and Vilar demonstrated that management of asthmatic children by a specialist (allergologist or pulmonologist) influenced significantly positively QL of children and parents probably owing to increased security [19,20]. The material presented revealed that the duration of specialist treatment has advantageous effects on the parents' QL. Our results found 77% children required emergency ambulant procedures. Our results correspond with those obtained by other authors, who found that factor significantly worsened parents' QL [7,9].

CONCLUSIONS

1. Burden due to child's chronic disease decreases considerably parents' QL, especially in the area of emotions.
2. Therapy of asthmatic child should be extended by psychoeducational activities addressed at his/her family.

REFERENCES

1. Johansson S, Haahtela T. Prevention of allergy and allergic asthma. World Allergy Organization Project Report and Guidelines. Chem Immunol Allergy. 2004;84:13-9.
2. Światowa strategia rozpoznawania, leczenia i prewencji astmy. Raport NHLBI/WHO. Aktualne wytyczne Global Initiative for Asthma (GINA 2005). Med Prakt. 2006;1.
3. Navale-Waliser M, Misener M, Mersman C, Lincoln P. Evaluating the needs of children with asthma in home care: the vital role of nurses as caregivers and educators. Public Health Nurs. 2004;21(4):306-15.
4. Volovitz B, Vichyanond P, Zhong NS. Allergy and asthma education Chem Immunol Allergy. 2004;84:163-83.
5. Kuiper S, Maas T, van Schayck C, Muris JW, Schönberger HJ, Dompeling E, Gijsbers B, van Weel C, Knottnerus JA. The primary prevention of asthma in children study: design of a multifaceted prevention program. Pediatr Allergy Immunol. 2005;16(4):321-31.
6. Weiss K, Haus M, Iikura Y. The coast of allergy and asthma and potential benefit of prevention strategies. Chem Immunol Allergy. 2004;84:184-92.
7. Bateman E. Asthma-related quality of life in the GOAL study: Baseline results. Eur Respir J. 2002;20 Suppl:38-46.
8. Juniper E, Guyatt GH, Feeny DH, Ferrie PJ, Griffith LE, Townsend M. Measuring quality of life in the parents of children with asthma. Qual Life Res. 1996;5(1):27-34.
9. Osman L, Silverman M. Measuring quality of life for young children with asthma and their families. Eur Respir J. 1996;21 Suppl.:35-41.
10. Reichenberg K, Broberg A. The Paediatric Asthma Caregiver's Quality of Life Questionnaire in Swedish parents. Acta Paediatr. 2001;90(1): 45-50.
11. Sawyer MG, Spurrier N, Kennedy D, Martin J. The relationship between the quality of life on children with asthma and family functioning. J Asthma. 2001;38(3):279-84.
12. Lohn Z, Ostrowski T, Wyczesany J. Przeżywanie sytuacji zdrowotnej przez dzieci chore na astmę i alergię i ich rodziców. In: Materiały z X Sympozjum Medycyny Psychosomatycznej. Kołobrzeg; 1994. p. 76-81.
13. Pilecka W. Choroba przewlekła dziecka, jego rozwój i interakcje rodzinne-model transakcyjny. In: Chodkowska M, editor Dziecko niepełnosprawne w rodzinie. Lublin: UMCS; 1995.
14. Dyga-Konarska M. Psychologiczne zagadnienia związane z astmą oskrzelową u dzieci i młodzieży. Nowa Klin. 1996;1:35-8.
15. Lal A, Kumar L, Malhotra S. Socioeconomic burden of childhood asthma. Indian Pediat. 1994;31(4):425-32.
16. Kumar C, Edelman M, Ficorelli C. Children with asthma: a concern for the family. MCN Am J Matern Child Nurs. 2005;30(50): 305-11.
17. Hederos C, Janson S, Hedlin G. Group disscusions with parents have long-term positive effects on the management of asthma with good cost-benefit. Acta Paediatr. 2005;94(5):602-8.
18. Mahajan P, Pearlman D, Okamoto L. The effects of fluticasone propionate on functional status and sleep in children with asthma and on the quality of life of their parents. J Allergy Clin Immunol. 1998; 102(1):16-7.
19. Storms B, Olden L, Nathan R, Bodman S. Effect of allergy specialist care on the quality of life in patients with asthma. Ann Allergy Asthma Immunol. 1995;75(6):491-4.
20. Vilar ME, Reddy BM, Silverman BA, Bassett CW, Rao YA, Chiaramonte LT, Schneider AT. Superior clinical outcomes of inner city asthma patients treated in an allergy clinic. Ann Allergy Asthma Immunol. 2000;84(3):299-303.

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