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ORIGINAL PAPER

ASSOCIATIONS BETWEEN THE QUALITY OF LIFE OF CHILDREN WITH CHRONIC DISEASES, THEIR PARENTS' QUALITY OF LIFE AND FAMILY COPING STRATEGIES

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Abstract

Aim: The survey aimed at determining the associations between the quality of life of children with chronic diseases, the quality of life of their parents and coping strategies used in the family. *Design:* A cross-sectional study. *Methods:* The study was performed as quantitative research using a questionnaire survey in chronically ill children (n = 288) aged 2–12 years and their parents. The following instruments were used: Pediatric Quality of Life Inventory, Pediatric Quality of Life Inventory Family Impact Module and Family Crisis Oriented Personal Evaluation Scales. *Results*: The association between the quality of life of diabetic children and their parents' quality of life, family functioning and the impact of the illness on the family was weak. Children with diabetes had the highest quality of life but the quality of life of their parents was lowest among all disease groups in the study. The lowest overall quality of life of children was noted among those with juvenile idiopathic arthritis. The strongest positive associations between internal coping strategies (i.e. reframing and passive appraisal) and children's and parents' quality of life was observed in the families of children with asthma. *Conclusions*: The weak association between children's and parents' quality of life and coping strategies pointed to their low effectiveness. The results suggest that relevant interventions should be used that promote selection of new coping strategies.

Keywords: quality of life, child, family, coping, asthma, juvenile idiopathic arthritis, diabetes mellitus.

Introduction

Chronic diseases are a heterogeneous group of conditions, characterized mainly by their persistence and a related lower quality of life (Nansel et al., 2008; Willems et al., 2009; Jafari et al., 2011; Kalyva et al., 2011; Haverman et al., 2012; Sand et al., 2012). Children with chronic diseases require long-term medical and nursing care combined with prolonged care from their parents. In the family, diseases may be perceived as stressful (Murphy, 2007; van den Tweel et al., 2008; Compas et al., 2012), changing situations and many aspects of the life of the child as well as the family; also changed are other family members' roles, overall lifestyle and, sometimes, even their values and norms (Vágnerová, 2008; Summers et al., 2005). According to family systems theory, the child is not the only individual affected by illness. Within the larger family system, there are several subsystems, such as the parent-child or marital relationship systems, which interact with one another (Gerson, 1995).

Long-term effects of children's diseases on their parents have been reported, such as a stronger bond between a mother and her chronically ill child, leading to an overprotective attitude and upbringing of the child (Hanson, Hanline, 1990), parental fatigue, mother's depression and anxiety (Quittner et al., 2001; Grey, 2009), sleep disturbances and tiredness leading to impaired daytime functioning (Meltzer, Moore, 2008), poor tolerance of frustration, attention and memory deficits (Smith, 2012), mood disorders, and quality of life changes (Hatzmann et al., 2008; Spore et al., 2012). Also noted were positive associations between pediatric chronic diseases and carers' mental health (Walders et al., 2006) or emotional functioning of the family (Orozco et al., 2013).

To manage stress related to their children's chronic diseases, parents have to make a greater effort referred to as coping. Guđmundsdóttir et al. (2006) studied parents of chronically ill children to reveal mostly emotional coping in 30% of them, stress avoidance in 19% and rational coping in 8%. In families of children with diabetes, Auslander et al. (1993) found one year after the diagnosis had been made that the most useful coping strategy leading to maintaining of family integration were cooperation

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in the family and an optimistic definition of the situation. Similarly, a study by Cavallo et al. (2009) showed that in parents of children with juvenile idiopathic arthritis, the most frequent coping strategy was aimed at maintaining family integration. Certain studies have placed great importance on determining what factors related to the child and the parent may influence the child's quality of life (Miller et al., 2006). However, only little attention has been paid to the use of coping strategies by the family with respect to the quality of life of both children and parents (Cavallo, 2009).

Aim

The survey aimed at determining the associations between the quality of life of children with chronic diseases, the quality of life of their parents and coping strategies used in the family.

Methods

Design

The study was performed as quantitative research using a one-time cross-sectional survey.

Sample

The sample comprised 288 children with chronic diseases (162 girls and 126 boys) and 288 parents of the children (225 females and 63 males). Intentional sampling was used to recruit the subjects, determined by the health care facilities' ability and willingness to participate and the parents' consent to enrollment. The other criteria for including parents in the study were having children aged 2 to 12 years with chronic diseases and visiting outpatient facilities with the children.

Data collection

The study was performed as quantitative research using a one-time cross-sectional survey. Children's quality of life was assessed with three types of the Pediatric Quality of Life Inventory™ (PedsQL™) version 4.0 for age groups 2–4 years (Varni, 1998a), 5–7 years (Varni, 1998b) and 8–12 years were used (Varni, 1998c). The PedsQL™ for ages 2–4 is a parent-proxy report comprising 20 items in the following domains: physical functioning, emotional functioning, social functioning and, where applicable, school (preschool) functioning. The questionnaire for ages 5–7 contains 23 questions in the same domains to be answered by children through the use of pictograms. Also the version for ages 8–12 consists of 23 items in the same domains. The items are scored (0 to 4 Likert scale) and transformed to a 0 to 100 scale, with higher scores meaning higher quality of life of that child. Parents' quality of life and the impact of a child's illness on the family were evaluated with the PedsQL™ Family Impact Module (PedsQL™ FIM) version 2.0 (Varni, 1998d). It comprises 36 items grouped into the following domains: physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worry, daily activities and family relationships. The items are scored and transformed to a 0 to 100 scale, with higher scores meaning better functioning (Varni, 2012). The parent health-related quality of life (HRQL) may be assessed as a summary of physical functioning, emotional functioning, social functioning and cognitive functioning; family functioning is a sum of daily activities and family relationships.

Coping strategies in the family were evaluated with the Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin et al., 1996). The instrument contains 30 items identifying behavioral strategies used by families rated on a 5-point Likert scale (from 1 – never to 5 – always). There are five subscales (i) acquiring social support – actively engaging in acquiring support from relatives, friends, neighbors and extended family; (ii) reframing – redefinition of stressful events to make them more manageable; (iii) seeking spiritual support – the ability to acquire spiritual support from religious or other sources; (iv) mobilizing family to acquire and accept help – seeking out resources in society and accepting help from others; and (v) passive appraisal – accepting and minimizing reactions to problematic issues. Internal (summary of reframing and passive appraisal) and external (summary of acquiring social support, seeking spiritual support and mobilizing family to acquire and accept help) coping strategies may be measured separately. Internal coping strategies refer to improving emotional balance, that is, reducing negative experiences. The external form of coping is related to problem-solving (McCubbin et al., 1996). The subscales are calculated and then totaled together, with higher total scores meaning more adaptive coping using a preferred strategy.

Data analysis

The data were processed with the IBM SPSS 20. The results were obtained using descriptive statistics (frequency [n], arithmetic mean [M], standard deviation [SD]). Subsequently, the analysis of variance (ANOVA) and chi-squared test were used. Significance was set at $p < 0.05$ for all analyses. Additionally, a correlation matrix was defined with the Spearman's correlation coefficient (r_s).

Results

Sociodemographic characteristics

In 93 children (32%), the diseases lasted for up to 1 year from diagnosis; the duration was 1 to 3 years in 107 children (37%) and more than 3 years in 88 children (31%).

The most frequent chronic disease was type 1 diabetes mellitus in 81 children (28%), followed by bronchial asthma in 75 children (26%), juvenile idiopathic arthritis (JIA) in 64 subjects (22%), epilepsy in 43 children (15%) and atopic eczema (AE) in 25 children (9%) receiving outpatient care. Given their small proportions, children with epilepsy and AE were brought into a single group referred to as others (n = 68; 24%). Their children's diseases were perceived as a burden by 214 parents (74%).

Children's quality of life

The highest and lowest total HRQL scores were found in children with diabetes (M = 75.63; SD = 14.52) and JIA (M = 65.72; SD = 12.14), respectively. There was no significant difference in the overall HRQL between girls and boys (p = 0.507). The highest and lowest total HRQL scores were in the age groups 8–12 years (M = 74.90; SD = 15.35) and 2–4 years (M = 68.63; SD = 12.83), respectively. The youngest children showed better psychosocial functioning scores (M = 67.39; SD = 13.65) than physical functioning scores (M = 67.34; SD = 18.00). In contrast, children aged 5–7 years had higher score in the physical domain (M = 73.50; SD = 20.97) than in the psychosocial domain (M = 69.97; SD = 14.64) and so had those in the 8–12 age category (physical health M = 77.98; SD = 18.17; psychosocial health M = 71.23; SD = 15.14). These differences between the physical and psychosocial HRQL domains were non-significant. Children of parents perceiving the disease as a burden for the family had significantly lower HRQL (M = 69.48; SD = 13.55) than those of parents not perceiving the disease as a burden (M = 80.15; SD = 14.15; Table 1). There were no significant differences in children's quality of life with regard to their parents' age and education.

Table 1 Children's HRQL

Factor	M	SD	95% CI	p-value
Disease				
Asthma	72.71	13.21	69.67–75.74	< 0.01
Diabetes	75.63	14.52	72.41–78.84	
JIA	65.72	12.14	62.68–68.75	
Epilepsy, AE	73.41	15.97	69.55–77.28	
Age				
2–4 years	68.64	12.83	65.85–71.42	0.011
5–7 years	72.11	14.21	69.23–74.98	
8–12 years	74.90	15.35	72.00–77.83	
Gender				
Girls	71.64	13.47	69.55–73.73	0.507
Boys	72.78	15.64	70.02–75.54	
Burden				
Yes	69.48	13.55	67.65–71.30	< 0.01
No	80.15	14.15	76.84–83.45	

M – mean; SD – standard deviation; JIA – juvenile idiopathic arthritis; AE – atopic eczema

Parents' quality of life and family impact

The greatest and smallest overall impact of diseases on the family was observed in parents of children with diabetes (M = 60.21; SD = 12.43) and asthma (M = 69.93; SD = 16.06), respectively (p = 0.001). Similar differences with regard to the type of diseases were noted when parent HRQL and family functioning were assessed separately (Table 2). Differences in parent HRQL and family functioning with regard to children's age categories and gender were non-significant s. Parents perceiving their children's disease as a burden had both parent HRQL and family functioning scores lower than those not perceiving the disease as burdensome (Table 2). Mothers showed a stronger perception of the impact on their quality of life (M = 63.78; SD = 15.03) than fathers (M = 74.34; SD = 16.00; p < 0.01). Mothers also showed a stronger perception of the impact on family functioning (M = 67.63; SD = 16.69) than fathers (M = 72.94; SD = 19.95; p = 0.025). There were no differences in HRQL with regard to children's age or parents' age and education.

Table 2 Parent HRQL and family functioning

Factor	M	SD	95 % CI	p-value
P-HRQL				
Disease				
Asthma	71.38	16.59	67.56–75.20	< 0.01
Diabetes	59.03	13.27	56.10–61.97	
JIA	69.30	14.34	65.71–72.88	
Epilepsy, AE	65.65	16.29	61.71–69.60	
Age				
2–4 years	65.68	15.88	62.24–69.14	0.133
5–7 years	63.92	16.21	60.64–67.21	
8–12 years	68.34	15.31	64.26–67.93	
Burden				
Burden yes	62.92	15.03	60.90–64.95	< 0.01
Burden no	75.28	14.69	71.85–78.70	
Family functioning				
Disease				
Asthma	71.20	16.69	67.36–75.04	0.006
Diabetes	64.21	15.55	60.77–67.65	
JIA	73.14	15.94	69.16–77.12	
Epilepsy, AE	67.52	17.35	63.32–71.72	
Age				
2–4 years	69.56	16.48	65.98–73.13	0.631
5–7 years	67.47	16.91	64.04–70.89	
8–12 years	69.39	16.65	66.22–72.57	
Burden				
Burden yes	66.62	16.54	64.39–68.85	< 0.01
Burden no	74.94	15.49	71.33–78.56	

M – mean; SD – standard deviation; JIA – juvenile idiopathic arthritis; AE – atopic eczema

Association between family impact and children's HRQL

There were positive correlations between children's overall HRQL and family impact, parent HRQL and family functioning in children with all disease types (Table 3).

Family coping

Internal coping strategies (i.e. those aimed at improving emotional balance) were most frequently used by families of children with JIA (M = 42.89; SD = 4.36) and least frequently by families of asthmatic children (M = 40.50; SD = 4.97). External coping strategies (i.e. those aimed at problem-solving) were most commonly applied in families with diabetic children (M = 41.14; SD = 10.87) and least commonly in families of children with JIA (M = 37.06; SD = 9.79). Social support was most frequently acquired by families of diabetic children (M = 24.96; SD = 6.09), the members of which also most often sought sources of help in the community and society and received help from others (e.g. agencies, social help programs, civic associations or self-help groups) (M = 10.19; SD = 3.47). Reframing was most commonly used by families of children with JIA (M = 31.00; SD = 4.75). Spiritual support was most frequently sought by families with asthmatic children (M = 6.95; SD = 3.22) (Table 4).

Table 3 Associations between parent HRQL, family functioning and family impact and children's HRQL

	HRQL dítěte			
	Asthma	**Diabetes**	**JIA**	**Epilepsy, AE**
Parent HRQL	0.550**	0.300**	0.422**	0.360**
Family functioning	0.460**	0.252*	0.492**	0.320*
Family impact	0.561**	0.283*	0.551**	0.422*

**p < 0.05; **p < 0.01; JIA – juvenile idiopathic arthritis; AE – atopic eczema*

Table 4 Family coping strategies

Domains	Diseases	M	SD	95 % CI	p-value
Acquiring social support	Asthma	21.99	5.39	20.75–2323	0.002
	Diabetes	24.96	6.09	23.61–26.31	
	JIA	21.67	5.96	20.18–23.16	
	Epilepsy, AE	22.16	5.92	20.73–23.60	
Reframing	Asthma	28.22	5.46	26.97–29.48	< 0.01
	Diabetes	29.32	4.42	28.34–30.30	
	JIA	31.00	4.75	29.81–32.19	
	Epilepsy, AE	27.51	5.22	26.25–28.78	
Seeking spiritual support	Asthma	6.95	3.22	6.20–7.69	0.275
	Diabetes	5.97	3.35	5.24–6.72	
	JIA	6.53	2.83	5.82–7.24	
	Epilepsy, AE	6.40	2.87	5.70–7.09	
Mobilizing of family	Asthma	8.81	2.56	8.22–9.40	0.006
	Diabetes	10.20	3.47	9.43–10.97	
	JIA	8.86	2.75	8.17–9.55	
	Epilepsy, AE	9.80	2.60	9.16–10.42	
Passive appraisal	Asthma	12.28	2.59	11.68–12.88	0.166
	Diabetes	11.46	2.23	10.96–11.95	
	JIA	11.90	1.92	11.41–12.37	
	Epilepsy, AE	11.89	2.28	11.33–12.43	

M – arithmetic mean; SD – standard deviation; JIA – juvenile idiopathic arthritis; AE – atopic eczema

When assessing problem-solving strategies with regard to perceived disease-related burden, symptomatic problem-solving (i.e. internal coping strategies) were found to be more frequently selected by families the members of which did not consider the disease as a burden (p = 0.016). The external form of coping was used equally by both groups (p = 0.234). There were no significant differences in the use of coping strategies with regard to children's age and gender. Similarly, parents' age or education had no impact on the use of coping strategies.

Association between family coping strategies and parent and children's quality of life

Effective use of internal coping strategies in families with asthmatic children confirmed a linear dependence between internal coping strategies and family impact, parent HRQL and children's HRQL, as well as a weaker correlation with family functioning (Table 5). In families with diabetic children, there was a moderate linear dependence between the use of internal coping strategies and family functioning, as well as a weak linear dependence between the internal strategies and parent HRQL and family impact. In case of children with JIA, weak positive associations between internal family coping strategies and parent HRQL and a moderate negative association between external strategies and family impact were noted. Correlations between the strategies and quality of life of children with JIA were not statistically confirmed.

Table 5 Associations between family coping strategies (internal, external) and parent and children's quality of life

Diseases	Coping strategies	Children's HRQL	Family impact	P-HRQL	Family functioning
Asthma	Internal	0.361**	0.477**	0.482**	0.336**
	External	-0.327**	-0.241*	-0.210*	-0.171*
Diabetes	Internal	0.258*	0.355**	0.356**	0.402**
	External	-0.031	0.012	0.053	-0.122
JIA	Internal	0.021	0.375**	0.350**	0.368**
	External	-0.223	-0.402**	-0.318*	-0.204
Epilepsy, AE	Internal	0.331**	0.322**	0.398**	0.386**
	External	-0.278	-0.401**	-0.321**	-0.287

$^{*}p < 0.05$; $^{**}p < 0.01$; *JIA – juvenile idiopathic arthritis; AE – atopic eczema*

Discussion

Every childhood disease has its own symptoms that may be subjectively unpleasant, limiting and specifically affecting an individual's quality of life (Verhoof et al., 2014). Chronic diseases represent permanent disability that may improve but cannot be cured. Thus, patients have to accept the illness as part of their identity and life (Vágnerová, 2008). The survey showed differences in subjectively perceived quality of life among children with various chronic diseases. The lowest and highest overall quality of life was found in children with JIA and diabetes, respectively. These findings are consistent with a study by Norrby et al. (2006) reporting lower quality of life in children with JIA as compared with asthmatic and diabetic children. Haverman et al. (2012) concluded that children with JIA had lower quality of life in all its domains than those without the condition. Also a meta-analysis by Le Bovidge et al. (2003) or a study by Gutierrez-Suarez et al. (2007) showed lower quality of life of children with JIA as compared with the healthy pediatric population.Children with diabetes were shown to have higher quality of life than their asthmatic counterparts in a study by Sawyer et al. (2004). Moreover, the quality of life was analyzed separately for three age groups (2–4 years; 5–7 years; 8–12 years). The different results may be related to the development of children as shown by Janse et al. (2008) stating that during their development, children change with respect to their needs, values, priorities and reactions to stress as well as their opinions on health and illness.

The greatest family impact was observed in families of diabetic children. Parents of children with JIA had lower quality of life in all the domains as compared with parents of children with asthma or epilepsy and AE. Both diabetes and JIA are conditions that place enormous demands on caring for the children and managing their behavior, ensuring their compliance with treatment or organizing their school and extracurricular activities; they are also associated with increased parents' concerns about unexpected deterioration of their children's health (Wiedebusch et al., 2008; Moreira et al., 2014). Unlike the present study, some authors have also reported a more profound impact of children's diseases on their parents. However, problems with physical and psychosocial functioning tend to increase mainly with more frequent exacerbations, hospital stays and visits to the emergency department due to unexpected deterioration of children's health status (Brown et al., 2006).

The association between children's quality of life and family functioning was confirmed by Hodaňová et al. (2008) who studied the quality of life in children aged 11–15 years and their subjective perception of family functioning. The results of their survey indicate that higher quality of family relations is related to an increase in children's quality of life. The present study also showed a positive relationship between family functioning and parents' quality of life and a weaker correlation with children's quality of life. Similarly, Crespo et al. (2011) reported only a weak to moderate correlation between the impact of illness on parents and their asthmatic children's quality of life. A study by Moreira et al. (2014) highlighted an interrelation between the child's illness and family functioning as well as an interrelation between family functioning and the child's psychosocial status.

The presented results regarding coping of diabetic children's parents are consistent with those in a study by Azar and Solomon (2001). Redefinition of problems to make them more manageable was most preferred by families of children with JIA. In such families, Cavallo et al. (2009) noted the highest coping scores for family integration and maintaining social support. However, the strategy that was correlated with a higher quality of life of the children (particularly in the psychosocial domain) was understanding the medical situation through communication and consultation with health professionals. The present study failed to confirm the significant correlation between family coping strategies and the quality of life of children with JIA. Spiritual support or passive appraisal were most frequently used by families of children with asthma. The findings concerning coping strategies and children's quality of life are consistent with those reported by Adams et al. (2004) and Van Den Ven et al. (2007). Sales et al. (2008) found a significant correlation between maternal coping (reframing) and an active approach to problem-solving and asthmatic children's higher quality of life, in particular emotional functioning. By contrast, a passive maternal approach was manifested by children's lower quality of life, especially more concerns about the self. The authors stated that active strategies were also associated with fewer unexpected severe symptoms of the condition. Thus, supporting active coping may promote not only children's quality of life but also their treatment (Sales et al., 2008).

Conclusion

The survey tried to point to the importance of the family context contributing to the quality of life of chronically ill children. It clearly showed that the quality of life of children and their parents is closely related and their perception of the disease as a burden is translated into the way of coping with that burden. However, the family coping strategy may not always be effective. The solution may be tailored health care provided by a multidisciplinary team in an outpatient setting where there is sufficient room for developing communication and support as needed by both children and their parents. Expert interventions should be aimed at promoting psychosocial health of both children and parents alike. This trend is characteristic for the so-called family-centered care. Extending care to the child's family is based on the understanding that the family is the child's primary source of strength and support and that the child's and family's perspectives and information are necessary for clinical decision-making of physicians, nurses and other health professionals (American Academy of Pediatrics, 2003; Pettoello-Mantovani et al. 2009).

Ethical aspects and conflict of interest

All respondents were informed about the objectives, how the results would be published and their anonymity protected. The subjects volunteered to participate and gave written consent to the use of their data. The authors declarethat they have no conflict of interest.

Author contribution

Conception and design (LS), data collection (LS), data analysis and interpretation (LS, RB), manuscript draft (LS, RB), critical revision of the manuscript (LS, RB), final approval of the manuscript (LS, RB).

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