Coll. Antropol. **35** (2011) Suppl. 2: 275–280
Professional paper

Parental Quality of Life in the Framework of Paediatric Chronic Gastrointestinal Disease

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ABSTRACT

Chronic gastrointestinal diseases, such as inflammatory bowel disease (IBD) and celiac disease (CD), might have impact not only on the affected child but also on their parents since inside the family framework, a change in each member may have influence on the whole system. The aim of this study was to test the hypothesis that parents whose children have IBD or CD will have a lower quality of life (QoL) compared to parents of healthy children, as well as that lower QoL will be found among parents who perceive lower health related quality of life (HRQOL) of their child. 55 parents of children with IBD, 49 of CD and 53 parents of healthy children were included in the study. Children were aged 7–18 years. In order to measure parental QoL, a Croatian version of the WHOQOL-BREF questionnaire was administered, with four domains: physical health, psychological health, social relationship and environment. The Total QoL was calculated as a sum of all domain items. The parent-proxy report of children's HRQOL, PedsQL^{TM} 4.0 Generic Core Scales was used. Main result shows that parents of children with IBD report a significantly lower psychological health, compared to parents of other children, and significantly lower physical health compared to parents of healthy children. Among parents of children with CD and parents of healthy children, better parental Total QoL was significantly correlated with better parental report of children's HRQOL, while for parents of children with IBD those associations were not found. Results of study show association between presence of the disease in offspring with poorer parental QoL, thus highlight the importance of supporting not only children with chronic disease but also involving their parents in psychosocial interventions, as well as supporting the patient's association groups which gather both children with chronic disease and their parents.

Key words: *quality of life, child, parents, inflammatory bowel disease, celiac disease*

Introduction

The major challenge for health care professionals who care for children and youth has become the management of chronic disease[1]. Among chronic gastrointestinal disease, there are inflammatory bowel disease (IBD) as well as celiac disease (CD). Celiac disease is a gluten enteropathy and a gluten-free diet is fundamental for curing it[2]. Compliance with this recommendation leads to the disappearance of medical symptoms and maintenance of remission. In contrary, IBD, which comprises ulcerative colitis and Crohn's disease, features periods of remission and episodes of relapse[3]. Relapse can occur despite treatment including regular taking of prescribed medicine[4]. Those unexpected flare-ups may require a high level of flexibility within families[5].

Inside the family framework, a change in each member may have influence on the whole system. A stable family is usually considered as being favourable for the child's development[6] and the children's health and well-being are inseparably connected to some of the parameters such as their parent's psychical, emotional and social health[7]. The family is the first social environment for the child[8], and as a unit system, it might react to the disease of their member. Thus, the childhood chronic disease may have impact on the psychosocial well-being of

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Received for publication May 30, 2011

children and their families[9]. Simultaneasly, parental own functioning may have one of the key roles in the child's psychological adjustment in the context of paediatric chronic medical conditions[10].

Looking at the family as a unit complex might lead us to utilize the biopsychosocial model introduced by G. Engles. It served as a determinant for many studies on how psychological and social factors influence the development, course and outcomes of the disease[11]. Thus, every attempt to identify potential psychosocial factors may contribute to better utilizations of this model into paediatric treatments of chronic disease and consequently provide possibilities for better child's health outcome. One of the parameters, which may give us an insight in a person's physical, psychological and social functioning is the concept of the quality of life (QoL) and like such, might be measured in order to access personal functioning.

According to the presence of a chronic disease in children and the impact it may have not only on children but also on their parents, we hypothesise that parents with children who have chronic gastrointestinal disorders (IBD or CD) will have a lower QoL compared to parents of healthy children. Since parents and children belong to the same dynamic family system, it is reasonable to expect that parental perceptions of the children's health related quality of life (HRQOL) might have been associated with their functioning. Thus, our second hypothesis is that the parental report of the better children's HRQOL will be connected with better parental QoL.

Participants and Methods

Participants were parents of children with IBD and parents of children with CD in which disease was diagnosed over a year ago, as well as parents of healthy children. All children were aged among 7 and 18 years and all parents included in the study were only those from a family consisting of both parents. The exclusion criteria were divorced parents and not living together, as well as parent's life treating health condition. The Ethics Committee of the Hospital approved the study protocol. Recruitment for the study was among parents of children with IBD and CD treated in the University Hospital Centre in Rijeka, during a one-year period in 2010. Parents were successively included during the scheduled visits of their children. Parents of healthy children were randomly recruited at regional schools. The participation in the study was voluntary and all participants signed an informed consent. Disease activity (DA) for IBD was calculated by a paediatrician according to the use of Paediatric Crohn disease activity index (PCDAI)[12] and Paediatric Ulcerative colitis activity index (PUCAI)[13].

In order to access parental QoL, a Croatian version of WHOQOL-BREF, with 26 items, was used for the current study[14]. The questionnaire measures QoL as perceptions of one's own position in life in relation to his goals, expectations, standards and concerns[15]. It has four domains (physical health, psychological health, social relationship and environment) and includes one item on Overall QoL and General Health. Total QoL was calculated as the sum of all domain items on WHOQOL-BREF.

The parent proxy-report of their children's HRQOL (PedsQL^{TM} 4.0 Generic Core Scales) is an instrument developed by Dr. James W. Varni[16]. It has 23 items and measures main domains on child's health, as well as their functioning at the school. The instrument is composed of 4 multidimensional scales (physical, emotional, social functioning and school functioning) and 3 summary results (total functioning, physical and psychosocial health). Psychosocial health comprised emotional, social and school functioning, while total functioning represents the sum of all scores. Higher scores indicate better children's HRQOL.

Statistical analysis was performed using SPSS 11.5.0. (SPSS Inc., 2002). Distribution of results for each subscale of WHOQOL-BREF and PedsQoL, including variability and data range, was examined. Spearman coefficient of correlation, eta coefficient of correlation, and chi-square were used as measures of association between variables. MANOVA and ANOVA were calculated to examine differences between three groups in dependent variables (domains of QoL and total QoL). In addition, paired t-test was used to examine differences between mothers and fathers when measuring the adjustment to children's illness.

Results

Participants were 55 parents of children with IBD and 49 parents of children with CD, as well as 53 parents of healthy children. The demographic characteristics of the participants are shown in Table 1. The differences in main measured parameters among groups were not significant. However, disease characteristic (activity and duration) of IBD and CD was different. Frequencies of DA for IBD were 76% children in remission, 16% had mild disease, while moderate and severe are each present in 4% of children. In the CD group, all children were rated as in remission since all were without symptoms and parent reported the following of a gluten-free diet. The majority of children with IBD had their disease from 1 to 3 years (41.5%) while majority of children with CD had the disease longer than 8 year (42.9%). The difference in disease duration between the two groups is statistically significant ($\chi^2=10.023$, df=3, $p=0.018$). No differences in the 4 QoL domains, neither the difference in Total QoL was found according to parental sex. The only statistically significant difference between mothers and fathers is in the Overall QoL ($p<0.005$), indicating that mothers of children with chronic disease have higher Overall QoL.

Analysis of variance show following statistical significance of average results in each parental QoL domain among groups of parents: a) Physical health: differences among groups were significant ($F_{(2,153-155)}=4.677$, $p<0.05$). Parents of healthy children have significantly higher physical health compared to parents of children

TABLE 1
DEMOGRAFIC CHARACTERISTICS, NUMBER AND PERCENTAGE OF PARTICIPANTS, ACCORDING TO CHILD'S DIAGNOSIS

	Diagnosis						p
	Healthy		IBD		Celiac		
	N	(%)	N	(%)	N	(%)	
Parental sex							
Men	20	(37.7)	25	(45.5)	19	(38.8)	0.676
Woman	33	(62.3)	30	(54.5)	30	(61.2)	
Parental age							
20–40 age	18	(34.0)	20	(37.7)	22	(45.8)	0.462
41 and more	35	(66.0)	33	(62.3)	26	(54.2)	
Parental education level							
Elementary and high school	38	(73.1)	45	(88.2)	37	(80.4)	0.151
University	14	(26.9)	6	(11.8)	9	(19.6)	
Parental employment status							
Employed	46	(88.5)	40	(76.9)	39	(84.8)	0.274
Unemployed	6	(11.5)	12	(23.1)	7	(15.2)	
Child's age							
7–12	24	(45.3)	21	(38.2)	30	(61.2)	0.057
13–18	29	(54.7)	34	(61.8)	19	(38.8)	
Child's sex							
Boys	28	(52.8)	28	(50.9)	20	(40.8)	0.431
Girls	25	(47.2)	27	(49.1)	29	(59.2)	

IBD – inflammatory bowel disease

with IBD, while differences between parents of children with CD and IBD, and also between CD and healthy children, were not found to be statistically significant; b) Psychological health: differences among groups were significant ($F_{(2,153-155)}=4.695$, $p<0.05$). Parents of children with IBD report significantly lower psychological health compared to parents of children with CD and parents of healthy children. The difference between parents of healthy children and parents of children with CD, in the level of psychological health, is not statistically significant; c) Overall QoL: difference among groups was significant ($F_{(2,153-155)}=5.106$, $p<0.01$). Higher Overall QoL was found in parents of healthy children compared to both parents of children with CD and IBD. Differences among others QoL results (social relationships, environment, Total QoL and General Health) were not significant among groups of parents.

Correlation coefficients of potential predictors and indicators of parental QoL domains are shown in Table 2. In parents of children with IBD, employed parents have better QoL in all domains. Parents of younger children with IBD have lower psychological health. Disease characteristics (activity and duration of IBD) were not significantly associated with any parental QoL domain. No significant connections between parental Total QoL with parent's perceptions of children's HRQOL were found, although such connections do exist with other parental QoL domains. Among parents of children with CD, those with higher education level and parents of girls have higher Total QoL. Duration of CD was not significantly associated with any parental QoL domain. All domains of parental QoL, as well as Total QoL, were connected with parental perceptions of children's HRQOL, in the way that higher parental QoL was associated with higher child's HRQOL. In the group of parents with healthy children, fathers have higher Total QoL than mothers. The parental perception of child's HRQOL was significantly correlated with parental QoL in all domains except in social relationships. The higher children's HRQOL was connected with higher parental Total QoL among parents of healthy children.

Discussion

Main findings of our study show that Overall QoL differed among parents of healthy and parents of children with chronic gastrointestinal disorders. However, the Total QoL was not significantly different, although differences among groups were significant in several parental QoL domains. Thus, parents of children with IBD had significantly lower physical health than parents of healthy children, and lower psychological health compared with the other two groups of parents. Since the presence of the child's chronic gastrointestinal disease was associated with lower parental QoL but not consistently through all QoL domains, our main hypothesis was thus only par-

TABLE 2
MEASURES OF ASSOCIATION BETWEEN SOCIODEMOGRAPHIC VARIABLES, PARAMETERS OF ILLNESS AND PARENT-PROXY REPORT ON PEDSQOL WITH WHOBREF QUALITY OF LIFE DOMAINS, ACCORDING TO CHILDREN'S DISEASE

		Total Qol	Overall Qol	Physical health	Psychological health	Social relationships	Environment
Inflammatory bowel disease Sociodemographic							
Parental:	Age	0.08	0.05	0.08	0.22	0.09	0.11
	Sex	0.19	0.08	0.28	0.21	0.06	0.11
	Education level	0.20	0.27	0.11	0.22	0.16	0.14
	Employment status	0.54**	0.34*	0.40**	0.37**	0.32*	0.53**
Child's:	Age	0.25	0.02	0.23	0.34*	0.25	0.07
	Sex	0.10	0.20	0.08	0.09	0.13	0.10
Disease's parameters							
	Duration	0.18	0.23	0.27	0.22	0.17	0.30
	Activity	0.10	0.20	0.13	0.03	0.05	0.08
PedsQoL							
	Psychosocial	–0.07	0.07	0.52**	0.22	0.50**	0.48**
	Total functioning	0.01	0.12	0.45**	0.30*	0.58**	0.44**
Celiac disease Sociodemographic							
Parental:	Age	0.22	0.04	0.07	0.16	0.07	0.22
	Sex	0.12	0.18	0.08	0.10	0.10	0.04
	Education level	0.39**	0.22	0.30*	0.15	0.23	0.25
	Employment status	0.16	0.02	0.15	0.07	0.13	0.12
Child's:	Age	0.11	0.06	0.04	0.02	0.10	0.02
	Sex	0.30*	0.17	0.20	0.22	0.24	0.22
Disease's parameters							
	Duration	0.21	0.24	0.13	0.27	0.23	0.28
PedsQoL							
	Psychosocial	0.58**	0.53**	0.51**	0.46**	0.45**	0.58**
	Total functioning	0.49**	0.49**	0.46**	0.36**	0.39**	0.49**
Healty children Sociodemographic							
Parental:	Age	0.19	0.05	0.15	0.07	0.10	0.23
	Sex	0.32*	0.20	0.34*	0.32*	0.09	0.32*
	Education level	0.23	0.05	0.24	0.29*	0.26	0.08
	Employment status	0.09	0.04	0.14	0.11	0.08	0.08
Child's:	Age	0.22	0.14	0.10	0.16	0.19	0.22
	Sex	0.03	0.17	0.03	0.05	0.04	0.10
PedsQoL	Psychosocial	0.43**	0.33**	0.48**	0.43**	–0.04	0.39**
	Total functioning	0.47**	0.34**	0.52**	0.46**	0.03	0.44**

*p<0.05, **p<0.01, QoL – quality of life

tially confirmed. Parents of children with IBD differ from parents of children with CD in psychological health and some variables, which might have influenced this result, will be discussed.

Disease parameters and parental QoL

Since almost a quarter of children with IBD had active disease while all children with CD were in remission, the found differences in psychological health might be due to the disease activity. It is known that, in the context of paediatric IBD, parental QoL might be associated with DA[17,18] although, in our study, this association was not confirmed. Another possible reason for differences might be due to disease course, especially due to the unpredictable nature of IBD and special demands of the disease itself. The unexpected IBD flare-ups may influence the parental psychological health, while on the other hand, CD may be controllable by following a strict gluten-free diet. The disease duration might also play an important role in the context of parental QoL, although, according to data from literature, it is not possible to state with certainty how parents' situation is influenced over time since different results were obtained[4]. Since our groups differ in disease duration, this may have some impact on our results. However, the duration of the disease in each group of parents was not significantly associated with parental QoL.

Child's characteristics and parental QoL

Child age has been linked with family's functioning in the way that poorer family functioning was significantly related to older child age in the context of paediatric chronic conditions[5]. Therefore, it might be proposed that child's age may have influence on parental QoL as well. However, child's age in our study was a significant parameter only concerning the psychological health among parents of children with IBD, in the way that parents of younger children have lower psychological health. This might be due to higher demands regarding the child's IBD treatment that fall upon parents when the child is younger. The connection between child's sex and parental Total QoL was found only in the group of children with CD. One of the plausible explaining ideas might be that girls are by nature more obedient, and thus more cooperative to follow a strict gluten-free diet making the presence of CD less associated with parental functioning.

Parents' sociodemografic characteristics and their QoL

Associations between paediatric IBD and parental employment status in all QoL domains were found. We might presume that employed parents have higher incomes that influence parental QoL perceptions, since expenses might be an important point in disease management. Thus, living expenses of more than a half of parents of adolescents with IBD have been affected by the disease treatment requirements[19]. Another possible explanation might be that having a job reassures parent's better QoL in other, broader, aspects of life, when unemployment might narrow the focus only to family and home situations. Since children with CD need to follow a special gluten-free diet it might be expected that financial issue somehow influences QoL of their parents as well. However, the connection between parental QoL and employment status in the CD group was not found, while a significant association exists with parental education level, but only in the domain of parental physical health. Since mothers are typically more involved in traditional caretaking responsibilities[18], it is a surprising cofound of our study that, among parents of children with chronic gastrointestinal disease, mothers have higher Overall QoL than fathers. However, this difference according to parental sex was not significant in 4 QoL domains or in Total QoL. Thus, the result of our study does not go in line with those findings that underscore the importance of examining maternal and paternal functioning separately in the context of IBD[18].

Parental report of children's HRQOL and parental QoL

Regarding the second hypothesis, it was found that parental Total QoL is associated with parental perceptions of child's HRQOL. It was also found that parental psychological health was associated with parent's perceptions of offspring's psychosocial functioning only when child has CD or child is healthy. Among parents of IBD, only parental psychological health was not connected with children's HRQOL while the other 3 parental QoL domains were significantly associated with it. This result is somehow surprising since data from previous study, in the context of paediatric IBD, showed that higher self-reported youth's QoL was connected with higher parental QoL only in the domain of mental health[17]. Our data might be elucidated in the similar context in which other study tried to understand why adolescents with IBD feel ambivalence towards their parent's concerns for them[20]. This involves awareness of an adolescent' coping strategy of avoidance and parents' lack of knowledge about their children's situations.

The other possible explanations of the result might also be seen as a parental response to responsibilities, limitations and parental stress which chronic child disease brings into the family system. This may go along with specific uncertainty experienced by parents about the course of IBD, which might generate parental exhaustion. Therefore, it is reasonable to presume that parents of children with IBD might benefit from additional support. Moreover, parent's involvement in clinical interventions may be crucial for improving the emotional well-being and HRQOL of their adolescent[10].

Limitations

A downside to our study was the small number of participants as well as not having longitudinal measurement in order to examine a possible change in parental QoL. It was beyond the range of the current study to assess parent's other parameters that might help to explain differences in parental QoL. According to the inclusion criteria that time since diagnosis must be at least one year, results do not represent the situation of parental functioning on newly diagnosed disease that might be connected to more stress. Since only married parents were included in the study these results may not be applied on single parenting. Future longitudinal researches could address many of the issues that are presented as a limitation in our study.

Conclusion

Because of a number of interacting factors, families may be unable to meet medical or social needs of their child[7], and psychosocial support of the family plays a very important role in the treatment of a child who has been diagnosed with chronic disease[4]. Since each determinant of the system might have an impact on the system itself, this gives us the possibility to, by influencing parents, possibly have an outcome on the child as well. Parents are important sources of support for youth, and therefore maximizing parental QoL may indirectly benefit the well-being of youth[17].

Our results of connection among presence of chronic gastrointestinal disease in offspring with poorer parental QoL in some domains, highlights the importance of supporting not only chronically ill children but also involving their parents in psychosocial interventions, as well as the need for supporting the patient's association groups which gathers both parents and their children with chronic gastrointestinal diseases.

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KVALITETA ŽIVOTA RODITELJA DJECE S KRONIČNIM BOLESTIMA GASTROINTESTINALNOG SUSTAVA

SAŽETAK

Kronične bolesti probavnog sustava, u koje spadaju upalne bolesti crijeva i celijakija, mogu imati utjecaj ne samo na oboljelu djecu nego i na njihove roditelje budući da promjene u bilo kojeg člana obitelji mogu utjecati na cijelu obitelj. Cilj ovog istraživanja je ispitati hipotezu da roditelji djece s upalnim bolestima crijeva i celijakijom imaju slabiju kvalitetu života u usporedbi s roditeljima zdrave djece. Pretpostavka je također da će kvaliteta života roditelja biti povezana s roditeljskim izvještavanjem o kvaliteti života njihove djece. U ispitivanje je uključeno 55 roditelja djece oboljele od upalnih bolesti crijeva, 49 roditelja djece s celijakijom i 53 roditelja zdrave djece. Za određivanje kvalitete života roditelja korištena je hrvatska verzija upitnika WHOQOL-BREF koja sadrži 4 domene. Ukupna kvaliteta života izračunata je kao zbroj svih rezultata na česticama domena. PedsQoL 4.0 korišten je za roditeljsko izvještavanje o kvaliteti života njihove djece. Rezultati pokazuju da roditelji djece oboljele od upalnih bolesti crijeva imaju značajno nižu domenu psihološkog zdravlja u usporedbi s roditeljima zdrave djece i one koja boluju od celijakije, kao i značajno nižu domenu fizičkog zdravlja u usporedbi s roditeljima zdrave djece. Među roditeljima djece s celijakijom i roditeljima zdrave djece bolja ukupna kvaliteta života roditelja značajno je povezana s njihovim izvještavanjem o boljoj kvaliteti života njihove djece, dok u roditelja djece s upalnim bolestima crijeva ta korelacija nije pronađena. S obzirom da rezultati ukazuju na povezanost prisutnosti kronične bolesti gastrointestinalnog sustava u djece sa slabijom kvalitetom života njihovih roditelja, poželjno je da uz oboljelu djecu, u psihosocijalne programe budu uključeni i roditelji.