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Original Article

Anxiety, Depression, and Quality of Life in Parents of Adolescents with Inflammatory Bowel Disease: A Longitudinal Study

Satomi Nomura,[1,2] **Yuri Hirano**,[1] **Ichiro Takeuchi**,[1] **Hirotaka Shimizu**,[1] **and Katsuhiro Arai**[1]

[1]Division of Gastroenterology, Center for Pediatric Inflammatory Bowel Disease, National Center for Child Health and Development, Tokyo, Japan
[2]Department of Child Nursing, National College of Nursing, Tokyo, Japan

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Correspondence to
Katsuhiro Arai
Division of Gastroenterology, Center for Pediatric Inflammatory Bowel Disease, National Center for Child Health and Development, 2-10-1 Okura, Setagaya, Tokyo 157-8535, Japan.
Email: arai-k@ncchd.go.jp

ORCID iDs
Satomi Nomura
https://orcid.org/0000-0002-4287-8781
Yuri Hirano
https://orcid.org/0000-0002-8146-5648
Ichiro Takeuchi
https://orcid.org/0000-0003-2198-913X
Hirotaka Shimizu
https://orcid.org/0000-0001-7173-0420
Katsuhiro Arai
https://orcid.org/0000-0002-6440-4640

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ABSTRACT

Purpose: The parents of adolescents with inflammatory bowel disease may experience impaired mental health and quality of life. This longitudinal study aimed to verify whether the mental health and quality of life of the parents of adolescents with inflammatory bowel disease declined when their children had active disease.
Methods: Sociodemographic data, parental anxiety, depression, and quality of life were analyzed using validated questionnaires for each variable. After the baseline survey, the second and follow-up surveys were conducted at 3 and 12 months, respectively. The active disease group comprised eight parents whose children had active disease during the baseline and second surveys. The remission group comprised 14 parents whose children remained in remission during both surveys. The improved group comprised nine parents whose children experienced active disease at baseline and remission during the second survey. Parental mental health and quality of life were compared among the groups.
Results: Significantly higher levels of anxiety were observed in the active disease group in all surveys (p<0.050). Although depression levels and quality of life did not differ significantly among the three groups, pairing the active disease group with other groups showed some large effect sizes.
Conclusion: Parents tended to experience decreased mental health and quality of life when their adolescents experienced active inflammatory bowel disease. Consequently, our hypothesis was partially verified. Therefore, parents need support when their children have active disease; this finding highlights the need for parental support systems.

Keywords: Adolescents; Inflammatory bowel disease; Mental health; Parents; Quality of life

INTRODUCTION

Adolescents with inflammatory bowel disease (IBD) often face difficulties related to its symptoms or treatment in their daily lives. These difficulties can negatively affect physical, psychological, and social well-being. Previous studies reported that adolescents experience various types of pain associated with intestinal inflammation, stress from painful medical interventions, and obstacles in school life, such as limited event attendance due to IBD

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Conflict of Interest

The authors have no financial conflicts of interest.

[1-4]. Moreover, these effects are likely to reduce the adolescents' quality of life (QOL), emphasizing the importance of providing proper support [5-7].

The parents of adolescents with IBD also face challenges [8,9]. For example, because it is difficult for adolescents to self-manage IBD as they are growing and developing, their parents are often responsible for disease management [10-12]. Thus, parents may feel pressured to take responsibility for understanding and supporting this condition, as well as treatment adherence both inside and outside the home [13-15]. Maintaining adequate mental health is another challenge faced by parents. Parents of adolescents with IBD experience high parenting stress or depressive symptoms due to stressful experiences related to their children's IBD [16,17]. Moreover, poor parental mental health leads to impaired QOL in adolescents with IBD [18-21]. In other words, both parents and adolescents are at risk of becoming trapped in a vicious cycle of mutual mental health impairment. Thus, providing support not only to adolescents with IBD but also to their parents is important.

The course of IBD is chronic, punctuated by repeated relapses and remissions, and is particularly unstable in children. Disease activity in children may affect parental mental health and QOL by triggering parental distress. Active IBD in adolescents is associated with parenting stress [22,23]. Parents may develop mental health or QOL problems secondary to their children's active disease because of increased parental burdens, such as increased hospital visits with their children and concerns about their health. However, whether active IBD in adolescents is regularly associated with changes in parents' mental health and QOL is not clear because most previous studies used single-point surveys to assess this association. We assumed that parental mental health or QOL would change depending on the presence of active disease at the time of the survey. Therefore, this longitudinal study aimed to verify the hypothesis that mental health and QOL among parents of adolescents with IBD decline when adolescents experience active IBD. The findings of this study provide a better understanding of the psychological conditions of parents of children with IBD. To evaluate mental health, we examined parents' anxiety and depression levels.

MATERIALS AND METHODS

Participants

Based on the World Health Organization definition, in this study, adolescents were defined as those aged between 10 and 19 years [24]. For this longitudinal study conducted over 1 year, adolescents with a confirmed diagnosis of IBD and their parents were recruited from a pediatric hospital to comprehensively assess their mental health and QOL. Adolescents with IBD and their parents were excluded from the study if they (a) refused to participate in the study, (b) could not read or answer questionnaires written in Japanese, or (c) had severe medical complications other than IBD. Forty-two adolescents and their parents who met the inclusion criteria agreed to participate in the baseline survey. After the baseline survey, the second and follow-up surveys were conducted at 3 and 12 months, respectively. Only parents who completed the baseline and secondary surveys in the longitudinal study were included in the analysis. Only the parental responses are presented in the current study; an analysis of the adolescents' responses is described separately.

The participants were divided into three groups of parents based on the presence or absence of active IBD in their children at the baseline and second surveys. The active disease group

included parents whose children had active disease during both surveys, the remission group included parents whose children's IBD remained in remission during both surveys, and the improved group included parents whose children experienced active IBD at baseline but achieved remission during the second survey. Primary pediatric gastroenterologists with sufficient experience in the medical management of pediatric IBD judged the presence or absence of disease activity in the adolescents based on the weighted Pediatric Crohn's Disease Activity Index (wPCDAI) or Pediatric Ulcerative Colitis Activity Index (PUCAI). Remission was defined as a wPCDAI score <12.5 or a PUCAI score <10. In the baseline survey, the active disease, remission, and improved groups included 8, 14, and 9 parents, respectively. The follow-up survey included 5, 14, and 6 parents in the active disease, remission, and improved groups, respectively.

Measures

1. Sociodemographic data

The parents answered questions about themselves in the baseline survey, including their age, years of education, employment status, and annual household income.

2. Parental anxiety

The Japanese version of the State-Trait Anxiety Inventory-Form JYZ (STAI-JZY) was used to assess parental anxiety. The reliability and validity of the STAI-JYZ have previously been verified [25]. The STAI-JZY comprises 40 items across two subscales (state and trait anxiety) rated on a four-point Likert scale ranging from almost never (1) to almost always (4). The state anxiety subscale indicates transient responses to situations that cause anxiety, whereas the trait anxiety subscale indicates a personality that is sensitive to anxiety. State anxiety was used as a measure of parental anxiety. Higher scores indicate a greater likelihood of anxiety.

3. Parental depression

Parental depression was assessed using the Japanese version of the Center for Epidemiologic Studies Depression Scale (CES-D). The reliability and validity of the CES-D have previously been verified [26]. This scale comprises 20 items regarding the participants' physical and mental states in the previous week, measured on a four-point Likert scale ranging from no days (0) to more than 5 days (3). The higher the score, the more intense the depression experienced by the respondent.

4. Parental QOL

The Japanese version of the World Health Organization Quality of Life 26 (WHOQOL26) scale was used to assess parental QOL. The internal consistency has been verified for the Japanese version of the scale [27]. The WHOQOL26 comprises 26 items measured on a five-point Likert scale ranging from not at all (1) to all times (5). A higher score indicates a higher QOL.

Data collection

The participants were recruited at a tertiary pediatric hospital in Japan between October 2017 and March 2020. The participants were contacted during regular visits and paper-based questionnaires were manually delivered. The participants were asked to complete the questionnaires and return them in person or by mail. Medical data regarding the adolescents were collected from their medical records during the baseline survey.

We conducted four surveys and included three surveys in the analysis. The baseline survey was conducted after informed consent was obtained. The second and follow-up surveys were conducted 3 and 12 months after the baseline survey, respectively.

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Statistical analysis

We conducted the following analyses to explore statistical differences among the three groups: (a) sociodemographic data and children's medical data were examined using Kruskal–Wallis and Fisher's exact tests; (b) differences in the means of anxiety, depression, and QOL scores in each survey were assessed using Kruskal–Wallis and Dunn–Bonferroni tests; and (c) differences in the repeated means of anxiety, depression, and QOL scores were examined using Friedman's test. We used r as an index of effect size, with values of 0.1, 0.3, and 0.5 indicating small, medium, and large effect sizes, respectively [28].

We conducted data analysis after excluding questionnaires with missing values. A *p*-values <0.050 were considered statistically significant. The analyses were conducted using IBM SPSS Statistics for Windows, version 28.0 (SPSS Inc.) and R Version 4.1.3. (IBD Ltd.).

Ethical considerations

The parents received oral and written explanations of the study. Written informed consent was obtained from all enrolled participants. The study was reviewed and approved by the Institutional Review Board of National Center for Child Health and Development (approval number: 1616).

RESULTS

Table 1 presents the sociodemographic data. The sociodemographic characteristics did not differ significantly among the groups. Most participants across all groups were middle class or higher.

Table 2 reports the medical data of the adolescents. The active disease group included adolescents with recent IBD diagnosis; however, the number of months elapsed since diagnosis did not differ significantly among the three groups. The disease activity differed significantly among the groups (p<0.010). The active disease and improved groups displayed decreased disease activity during the survey period. The medical treatments did not differ significantly among the groups.

Table 1. Participants' demographic data

Variable	Active disease group	Remission group	Improved group	*p*-value*
Parent				
Age (y)	43 (39–52)	45 (43–50)	48 (45–51)	0.440
Education (y)	14 (14–16)	16 (14–16)	14 (13–16)	0.520
Employment status				
Employment	7 (87.5)	9 (64.3)	9 (100.0)	
Non-employment	1 (2.5)	5 (35.7)	0 (0.0)	
Adolescent				
Age (y)	13 (11–14)	14 (12–14)	15 (13–16)	0.150
Sex				
Male	3 (37.5)	8 (57.1)	3 (33.3)	
Female	5 (62.5)	6 (42.9)	6 (66.7)	
Family				
Household income (ten thousand yen)				
300–700	2 (25.0)	4 (28.6)	2 (22.2)	
700–1,000	2 (25.0)	6 (42.9)	3 (33.3)	
>1,000	4 (50.0)	2 (14.3)	1 (11.1)	
No response	0 (0.0)	2 (14.3)	3 (33.3)	

Values are presented as number (%) or median (interquartile range).
*Kruskal–Wallis test.

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Table 2. Comparisons of medical data in the active disease, improved, and remission groups

Adolescents medical data	Active disease group	Remission group	Improved group	*p*-value
Disease activity				
Baseline				
wPCDAI	25.0 (22.5–33.1)	0 (0–2.5)	15.0 (15.0–15.0)	<0.001*
PUCAI	15.0 (15.0–15.0)	0 (0–2.5)	37.5 (23.8–68.8)	0.010*
Second				
wPCDAI	17.5 (15.0–33.1)	0 (0–0)	0 (0–0)	<0.001*
PUCAI	22.5 (20.0–20.0)	0 (0–0)	0 (0–1.3)	0.020*
Follow-up				
wPCDAI	7.5 (0–16.3)	0 (0–0)	20.0 (10.0–10.0)	0.010*
PUCAI	3.8 (0–0)	0 (0–2.5)	0 (0–0)	0.360*
Friedman test				
wPCDAI	*p*=0.020	*p*=0.220	*p*=0.370	
PUCAI	*p*=0.140	*p*=0.610	*p*=0.050	
Time elapsed since diagnosis (mo)	33 (7–41)	33 (15–54)	33 (15–54)	
Classification of IBD				
Crohn's disease	6 (75.0)	9 (64.3)	3 (33.3)	0.210†
Ulcerous colitis	2 (25.0)	5 (35.7)	6 (66.7)	
Medical treatment				
Nutritional therapy				
Received	2 (25.0)	7 (50.0)	4 (44.4)	0.430†
Not received	6 (75.0)	7 (50.0)	5 (55.6)	
Steroid therapy				
Received	2 (25.0)	2 (14.3)	2 (22.2)	0.860†
Not received	6 (75.0)	12 (85.7)	7 (77.8)	
Biological therapy				
Received	7 (87.5)	11 (78.6)	6 (66.7)	0.660†
Not received	1 (12.5)	3 (21.4)	3 (33.3)	

wPCDAI: weighted Pediatric Crohn's Disease Activity Index, PUCAI: Pediatric Ulcerative Colitis Activity Index, IBD: inflammatory bowel disease.
*Kruskal–Wallis test. †Fisher's exact test.

Figs. 1-3 show the results of comparisons between parental anxiety, depression, and QOL scores for each survey. Anxiety levels differed significantly among the three groups during the survey period ($p<0.050$), and the effect size was large. Although no significant differences were observed in depression levels and QOL among the three groups, the effect sizes were large when the active disease group was paired with the other groups in the second and follow-up surveys. Friedman's test showed no significant differences in anxiety, depression, and QOL scores among all groups.

DISCUSSION

This study was conducted to verify whether the mental health and QOL in parents of adolescents with IBD declined when their children had active disease. Parental anxiety differed between the three groups and large effect sizes were observed for depression when the groups were paired with the active disease group. Thus, our hypothesis was partially verified.

The parents in the active disease group had significantly higher anxiety levels than those in the remission group during the survey period. In addition, the anxiety scores of the active disease and improved groups in the baseline survey had similar distributions; however, the scores of the improved group were lower than those of the active disease group in the second survey when active disease in the improved group had resolved. In other words, parents experienced high anxiety when their children experienced active IBD. This result is similar

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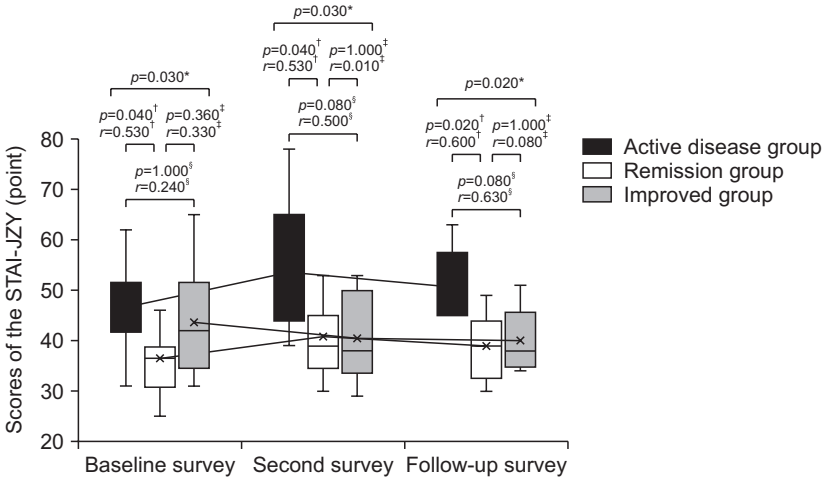

Fig. 1. The vertical axis represents the range of STAI-JZY state anxiety scores. The STAI–JZY scores did not differ significantly in any group during the survey period (active disease group, p=0.500; remission group, p=0.340; improved group, p=0.120). *p-value of the Kruskal–Wallis test. †p-value of the Dunn–Bonferroni test and r calculated by pairing the active disease and the remission group. ‡p-value of the Dunn–Bonferroni test and r calculated by pairing the remission and improved groups. §p-value of the Dunn–Bonferroni test and r calculated by pairing the active disease and improved groups.
STAI-JZY: State-Trait Anxiety Inventory-Form JYZ.

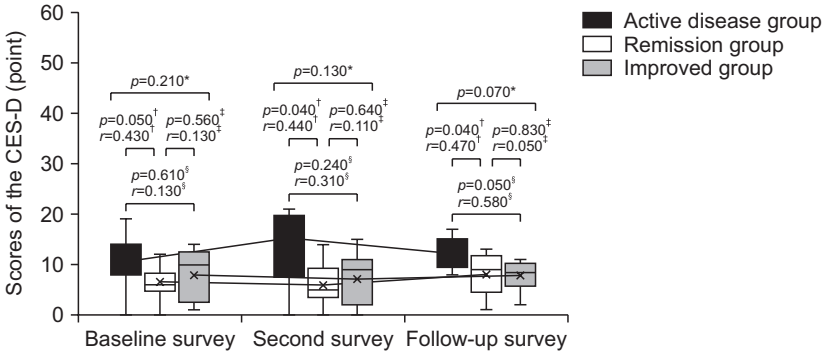

Fig. 2. The vertical axis represents the range of CES-D scores. The CES-D scores did not differ significantly in any group during the survey period (active disease group, p=0.850; remission group, p=0.350; improved group, p=0.060). *p-value of the Kruskal–Wallis test. †r calculated by pairing the active disease and remission groups. ‡r calculated by pairing the remission and improved groups. §r calculated by pairing the active disease and improved groups.
CES-D: Center for Epidemiologic Studies Depression Scale.

to those of previous studies [29,30]. It is easy to imagine that parents feel anxious when their children have active IBD because they witness their children experiencing IBD symptoms. Previous studies also reported that the parents of children with IBD worry about their children's condition and develop high levels of anxiety [31]. Similar parental characteristics were reflected in our results. Parents in the active disease group continuously experienced high levels of anxiety during the active disease period. To our knowledge, no other study has assessed this temporal aspect of parents' psychological state. Parental psychological problems, including anxiety, make it more difficult for parents to manage their children's disease [32]. Parental anxiety and children's disease activity may have interacted and concurrently observed in the active disease group during this period. Thus, lower parental anxiety may help prevent IBD in children. Therefore, parents must receive support to maintain their mental health during periods when their adolescents have active disease to avoid exacerbating their anxiety and children's symptoms. We recommend that medical workers provide proper support not

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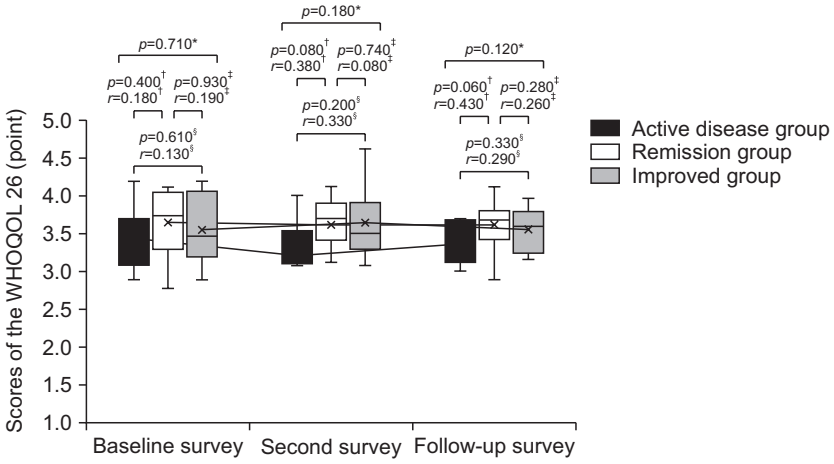

Fig. 3. The vertical axis represents the range of WHOQOL26 scores. The WHOQOL 26 score did not differ significantly in any group during the survey period (active disease group, p=0.950; remission group, p=0.910; improved group, p=0.960). *p-value of the Kruskal–Wallis test. †r calculated by pairing the active disease and remission groups. ‡r calculated by pairing the remission and improved groups. §r calculated by pairing the active disease and improved groups.
WHOQOL26: World Health Organization Quality of Life 26.

only to children with IBD but also to their parents when children experience active disease. Medical workers should consider the need for parental support.

Parental depression did not differ significantly among the three groups. In other words, the parents of adolescents with IBD did not have severe depression, even when their adolescents experienced active IBD. This finding is consistent with that of a previous study [18]. Although the sample size in this study was small, and depression levels did not differ significantly, the effect size suggests that parents are more likely to be depressed when their children have active IBD. Parents are likely to experience mental and physical fatigue when adolescents develop active IBD, which heightens depressive symptoms in the parents [33]. Parental depression may lead to inadequate childcare or mental impairments in their children [34,35]. Therefore, controlling IBD in children and minimizing depressive symptoms in parents are important goals.

The parental QOL also did not differ significantly among the three groups. This result differs from that of a previous study that reported low QOL in the parents of adolescents with active IBD [36]. Parents in the active disease group showed scores similar to the Japanese average scores on the WHOQOL26 scale and the scores of parents of children with developmental disabilities [27,37]. In other words, parental QOL was relatively unimpaired even when their children had active IBD. Some parents may have developed resilience to their children's IBD during the course of the disease, resulting in the lack of effect of active disease in children on parental QOL. Additional studies are needed to further clarify parental QOL, as it may change easily due to the adolescent's condition, family functioning, support provided, and parental mental health [38,39].

Study limitations

This study had a small sample size; therefore, the results may not be broadly applicable and should be interpreted with this limitation in mind. Parental anxiety, depression, and QOL are affected by various factors other than active IBD in adolescents. However, the present study did not assess other factors. The possibility of sampling bias cannot be excluded because

the data were collected from a single institution. Parental psychological status may vary with the disease stage. However, this was not factored into the study because the analysis did not adjust for the onset time of IBD in the children. Future longitudinal studies should be conducted to assess parental mental health and QOL at an early period after the onset of IBD in their children and to explore additional and varied factors correlated with parental stress and depression.

Conclusion

Parents reported a decline in mental health when their adolescent children had active IBD. Our hypothesis, that mental health and QOL in parents of adolescents with IBD decline when their children have active IBD, was partially verified. Our results emphasize the importance of providing support to parents, as it may contribute to the protection and maintenance of parental mental health, enabling them to provide better care for their children with active disease.

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