

Study on the Relationship Between Guardians' Worries about the Disease and Family Support and Psychological Endurance of Children with Inflammatory Bowel Disease

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Abstract. This study explored the connection between disease uncertainty and family/mental resilience in 180 guardians of children with IBD. Guardians completed the Mishel Illness Uncertainty Scale (MUIS-FM), Family Resilience Index Scale (FHI), and Connor-Davidson Mental Resilience Scale (CD-RISC). Results showed high disease uncertainty, with top scores for uncertainty (84.3%), lack of information (76.9%), unpredictability (74.0%), and complexity (68.2%). Guardians' mental resilience significantly linked to family resilience. Multiple regression analysis revealed family resilience's challenge dimension and mental resilience's tenacity and strength as key predictors of disease uncertainty. The study concludes that guardians of children with IBD face significant disease uncertainty, tied to lower family and mental resilience. Interventions should focus on enhancing family support and psychological adaptability to improve their monitoring experience, ultimately aiding in better management of their children's condition and overall well-being. This highlights the importance of a holistic approach in supporting these families, addressing not only medical needs but also the psychological and emotional aspects of caring for a child with a chronic illness.

Keywords: Family strength, Pediatric IBD, Caregiver burden, Uncertainty.

1. Introduction

Inflammatory bowel disease (IBD), encompassing Crohn's disease and ulcerative colitis, is a chronic, idiopathic intestinal inflammation presenting with symptoms like abdominal pain, diarrhea, bloody stools, and weight loss[1,2]. Its challenging treatment, recurrent nature, and potential for malignancy make it a significant health concern, especially as pediatric cases rise. IBD profoundly impacts children's physical and mental well-being, while also posing substantial psychological challenges to their caregivers[3,4]. The stress on caregivers, often stemming from limited understanding of IBD's specifics, treatment, and prognosis, is gaining increased societal attention[5].

This lack of understanding, termed "disease uncertainty," hinders informed decision-making and can weaken caregivers' ability to seek crucial information[6]. Consequently, this uncertainty can disrupt caregivers' functioning, leading to adverse psychological states and even extreme behaviors, ultimately diminishing their quality of life and potentially hindering the child's treatment and recovery. While research has explored disease uncertainty in various medical fields, its impact on caregivers of children with IBD remains under-researched[7]. This study aims to address this gap by examining the relationship between illness uncertainty and family strength and psychological resilience among these caregivers[8].

2. Materials and methods

2.1. General data

The study included 180 guardians who cared for 112 children with inflammatory bowel disease (IBD), including 62 (55.4%) with Crohn's disease (CD) and 50 (44.6%) with ulcerative colitis (UC). The age range of the children was 1-14 years old, all of whom met the 2019 expert consensus criteria for diagnosis and treatment of IBD in children[9]. The condition was stable and the data were complete during follow-up. Exclusion criteria included combined diabetes, cardiovascular and cerebrovascular diseases, hepatic and spleen dysfunction, infectious diseases, blood or immune system diseases, and the use of platelet-affecting drugs such as ticlopidine, heparin, aspirin and dipyridamole in the past two weeks. The gender distribution of children was 68 males (60.7%) and 44 females (39.3%), and the mean age of onset was (9.8 ± 2.3) years.

Guardians must meet the following conditions: age 18-70 years old, junior high school education or above, be the immediate family member and primary caregiver of the child, understand the child's condition, and be in good health to complete the study assessment. Those with severe physical diseases or mental disorders were excluded. The final 180 guardians included ranged in age from 25-68 years, with a mean age of (46.5 ± 12.8) years, including 82 males (45.6%) and 98 females (54.4%); The marital status is mainly married (138, 76.6%), the education level is college degree or above accounts for 58.3% (105), and the monthly family income is concentrated between 2,000 and 6,000 yuan (115, 63.8%).

2.2. Evaluative methods

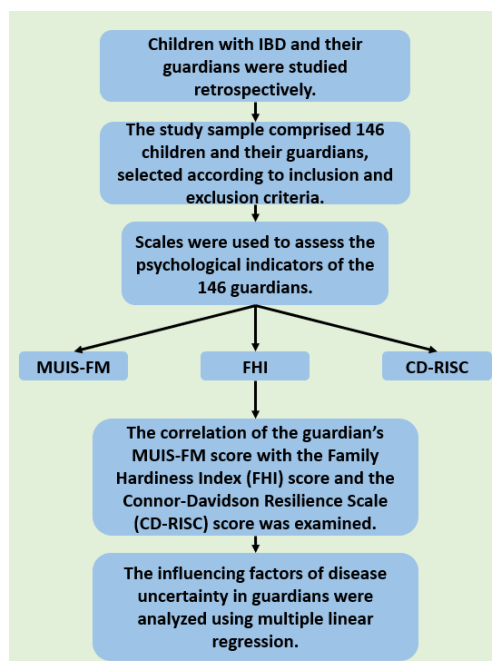


Figure 1: Method flow chart

During outpatient visits or hospital stays, guardians were assessed using various scales, administered by a dedicated gastroenterology nurse. Prior to the assessment, the nurse explained the purpose and procedures of the test to the guardian. Standardized instructions were used for each scale, and any content that the guardian found unclear was further explained. Once the guardian fully understood the assessment, they independently completed all scales based on their actual experiences, within a 30-minute time frame. Completed forms were collected immediately. Out of 180 scales distributed, 180 were successfully retrieved, achieving a 100% response rate. The study's methodology is illustrated in Figure 1.

2.3. Assessment content and tools

Perception of illness uncertainty was measured using the Chinese version of Mishel's Uncertainty in Illness Scale-Family Member form (MUIS-FM)[10]. This scale evaluates the guardian's level of uncertainty regarding the disease across four domains: complexity, uncertainty, unpredictability, and lack of information. The MUIS-FM comprises 33 items, with a total score ranging from 33 to 165. Higher scores indicate a greater degree of perceived uncertainty. Domain scores were calculated as follows: $(\text{average score of domain} / \text{highest possible score of domain}) \times 100\%$.

Family resilience was assessed using the Family Hardiness Index (FHI), which measures the internal strengths of family members[11]. The FHI comprises three domains: commitment, challenge, and control, across 20 items. A 4-point Likert scale was employed for scoring, where 1 indicated strong disagreement, 2 indicated disagreement, 3 indicated agreement, and 4 indicated strong agreement. Items 1, 2, 3, 8, 10, 14, 16, 19, and 20 were reverse-scored, while the remaining items were scored positively. Higher total scores reflected greater family resilience. The Cronbach's alpha for this scale was 0.80.

Psychological resilience was measured using the Connor-Davidson Resilience Scale (CD-RISC), developed by Connor and Davidson[12]. This scale, comprising 25 items, was adapted for Chinese populations by Liu et al[13]. and assesses three domains: tenacity, strength, and optimism. The total score is the sum of all item scores. The scale demonstrated good internal consistency (Cronbach's $\alpha = 0.89$) and test-retest reliability ($r=0.87$). It measures positive psychological traits that promote adaptation to adversity, such as illness and negative events. A 4-point scoring system was used, with total scores ranging from 0 to 100. Higher scores indicate greater mental resilience.

2.4. Statistical methods

All data were analyzed using SPSS version 21.0. Normally distributed continuous data were presented as mean $\pm$ standard deviation, while non-normally distributed continuous data were expressed as median (interquartile range, P25, P75). Categorical data were presented as frequencies or percentages. The Spearman correlation coefficient was used to assess correlations. Statistical significance was set at a two-tailed alpha level of 0.05.

3. Results

3.1. General information of the guardian

Among the 180 guardians surveyed, the majority were female (54.44%), aged 45-59 (43.33%), had a college education or higher (58.33%), were unemployed or retired (52.78%), and had a family monthly income of 2001-3000 (17.77%), as shown in Table 1.

Table 1: General information of the guardian

Variable	Items	Number of people	Percentage
Sex	Male	82	45.56
	Female	98	54.44
Age	<45	45	25.00
	45–59	78	43.33
	≥ 60	57	31.67
Marital status	Married	138	76.66
	Unmarried	42	23.33
Educational level	Junior and senior secondary	75	41.67
	College degree or above	105	58.33
Work status	Be on the job	85	47.22
	Unemployed or retired	95	52.78
Family monthly income	<1000	22	12.22
	1000–2000	43	23.88
	2001–3000	32	17.77
	>3000	83	46.11

3.2. Guardian's MUIS-FM rating

The MUIS-FM scores of the 180 guardians in this study ranked from lowest to highest in the following order: complexity, unpredictability, lack of information, and overall uncertainty, as

presented in Table 2.

Table 2: Guardian's MUIS-FM rating

Items	Number of entries	Divide entries	Dimension scores	Average Score	Score ranges
Unpredictability	13	1.6 (1.3-1.9)	21 (18-24)	20.8 (3.5)	15-28
Lack of information	5	3.8 (3.2-4.3)	19 (16-22)	18.5 (3.2)	10-25
Complexity	7	3.1 (2.7-3.5)	22 (19-25)	21.9 (4.0)	14-30
Uncertainty	8	4.2 (3.8-4.6)	34 (30-37)	33.7 (5.8)	20-45
Total points	33	2.9 (2.6-3.2)	96 (88-104)	94.9 (11.2)	70-128

3.3. Guardian's FHI rating

FHI averaged an overall score of 47.1, as shown in Table 3.

Table 3: Guardian's HFI rating

Items	Number of entries	Divide entries	Dimension scores	Average Score	Score ranges
Commitment	9	2.4 (2.1-2.7)	22 (19-25)	21.3 (4.1)	12-28
Control	6	2.2 (1.9-2.5)	13 (11-15)	13.1 (3.0)	7-20
Challenge	5	2.5 (2.2-2.8)	13 (11-15)	12.7 (2.7)	6-18
Total points	20	2.4 (2.1-2.6)	48 (43-53)	47.1 (7.3)	30-64

3.4. Guardian's CD-RISC rating

The average CD-RISC score in this study was 68.2, as shown in Table 4.

Table 4: Guardian's CD-RISC rating

Items	Number of entries	Divide entries	Dimension scores	Average Score	Score ranges
Tenacity	13	2.6 (2.3-2.9)	34 (29-38)	33.5 (6.5)	18-50
Strength	8	3.0 (2.6-3.4)	24 (21-27)	23.8 (5.1)	12-35
Optimism	4	3.2 (2.8-3.6)	13 (11-15)	12.9 (2.9)	5-18
Total points	25	2.8 (2.5-3.1)	70 (63-77)	68.2 (9.4)	45-90

3.5. Results of regression analysis of influencing factors of guardians' disease uncertainty in pediatric IBD patients as caregivers

In order to determine the relationship between the total score of illness uncertainty and various factors, this study used multiple linear regression analysis to analyze the influence of independent variables (general information, family resilience and mental resilience) on dependent variables (total score of illness uncertainty). The results are summarized in Table 5.

Table 5: Multiple linear regression analysis

Items	B	SE	β	t	P
FHI-Challenge	-0.75	0.15	-0.31	-4.92	<0.001
CD-RISC-Tenacity	-0.42	0.08	-0.35	-5.25	<0.001
CD-RISC-Strength	-0.38	0.09	-0.24	-4.22	<0.001
Family monthly income	-0.01	0.003	-0.08	-1.12	0.265

4. Conclusions

In short, caregivers of children with inflammatory bowel disease (IBD) have great ambiguity in their cognition of the disease, which is closely related to the adaptability of families and the psychological endurance of caregivers. Given the significant cognitive ambiguity faced by caregivers of children with IBD, there is an urgent need to focus on the family interactions and mental health of these caregivers.

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