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Care needs profiles of Crohn's disease patients and their associations with symptom clusters, post-traumatic growth, and family function: a latent profile analysis

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Abstract

Background and aims The care needs of patients with Crohn's disease (CD) may be heterogeneous. This study aimed to explore the latent class of care needs of patients with CD and differences in their characteristics and to analyze the factors influencing the different latent classes.

Methods A convenience sampling method was used to select 250 patients with CD who attended a tertiary-level hospital in Nanjing from August to November 2024 for the study. They were surveyed via the *General Information Questionnaire*, the *Crohn's Disease Care Needs Scale (CD-CNS)*, the *Inflammatory Bowel Disease (IBD) Patient Symptom Clusters Assessment Scal*e, the *Family Adaptability and Cohesion Scale (FACES)*, and the *Post-traumatic Growth Inventory (PTGI)*. The latent classes of care needs of CD patients were identified via *latent profile analysis (LPA)*, and the factors influencing their latent classes were analyzed via multiple logistic regression analyses.

Results (1) The LPA results revealed that the care needs of CD patients were divided into three profiles as the best model fitting indicators: the "low-care-needs-adaptation group" ($n=96$, 38.4%), the "moderate-care-needs-growth group" ($n=81$, 32.4%), and the "high-care-needs-distress group" ($n=73$, 29.2%). (2) Regression analyses revealed that current disease status, the presence of a stoma, symptom burden, family adaptability and cohesion, and post-traumatic growth (PTG) were influential factors in different latent classes.

Conclusion There is significant heterogeneity in the care needs of CD patients. Care needs to focus on patients with high care needs and enhance their symptom management and psychological interventions to improve their PTG and reduce their disease burden.

Keywords Crohn's disease, Care needs, Symptom clusters, Latent profile analysis, Post-traumatic growth, Family adaptability, Family cohesion

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Introduction

Crohn's disease (CD) is a chronic nonspecific intestinal inflammatory disease with unclear etiology and pathogenesis [1]. In recent years, the incidence of CD has been increasing globally [2], and China, as an Asian country with a high incidence of CD [3], has an average annual incidence rate of approximately 1.22 per 100,000 people [4], with the rate still increasing. The disease is recurrent and incurable [5], and long-term maintenance treatment places an enormous economic burden on patients [6], while symptoms such as chronic diarrhea, abdominal pain, and fatigue can seriously affect patients' work, life, and socialization [7]. Under the combined effects of various factors, CD patients generally have a large psychological burden [8], and both the body and mind are in a state of high demand.

Care needs refer to all kinds of help and services that patients need to be provided in the process of disease diagnosis, treatment, and follow-up, including physiological, informational, emotional, psychological, and social aspects [9]. Focusing on care needs during an illness can help individuals cope better with their illness [10]. Research [11–12] has shown the existence of numerous unmet needs in people with CD. For example, a systematic review revealed that patients with CD have numerous informational, medical, and psychological needs at different stages across their lifespan and urgently require personalized supportive care interventions from professionals [13]. However, providing individualized supportive care to patients is premised on an accurate assessment of each patient's needs. Previous widely used tools for assessing care needs are only applicable to cancer patients, such as the *34-item Supportive Care Needs Survey (SCNS-SF34)* [14], and there is a lack of appropriate tools to measure the care needs of patients with CD. The *Crohn's Disease Care Needs Scale (CD-CNS)*, a specific scale for assessing the care needs of CD patients, was previously developed by our research team through a systematic literature review, qualitative interviews, and the Delphi method [15]. CD-CNS reliability and validity have been demonstrated in evaluations and were determined to be suitable for assessing the care needs of CD patients in a Chinese clinical research setting [15]. Therefore, the CD-CNS was used in this study to assess the care needs of patients with CD.

In addition, previous research on CD care needs has been limited to the use of high and low scores on scales to determine individuals' level of need [16], a variable-centered approach that ignores the heterogeneity of individuals at different levels. In contrast, *latent profile analysis (LPA)* is an individual-centered statistical method that explores the underlying group structure and thus identifies groups with different characteristics, allowing subgroup classification based on different characteristics of variables [17]. This approach allows for the identification of CD patients with different characteristics, thus enabling the provision of more targeted care needs. Compared with cluster and factor analyses, it is more accurate, objective, flexible, and comprehensive [18–19].

Furthermore, few existing studies have assessed the care needs of people with CD at multiple levels, including patients' physical and mental health and family. *Social-ecological theory* [20] states that changing only the intrinsic level of an individual has a limited effect on maintaining long-term health behaviors and that multiple levels of intervention together are the most effective way to change health behaviors. Specifically, the care needs of people with CD may be influenced by both the individual level (e.g., sociodemographic, disease-related, and psychological factors) and the interpersonal level (e.g., family factors). However, the previous studies on psychological factors of care needs mostly focused on negative aspects [21], and positive studies were scarce. With the rise of positive psychology, studies have found that patients with chronic diseases will also experience positive psychological changes through complex cognitive adjustments after struggling with traumatic events such as diseases, which in turn promotes them to adopt a positive attitude to re-understand themselves and deal with diseases and focus on physiological, psychological, and social needs to reshape their lives [22, 23]. The CD is undoubtedly a traumatic event for patients, and it may also have an impact on their physical and psychological needs. Therefore, this study explored the latent classes of care needs of patients with CD based on LPA and analyzed their influencing factors at multiple levels concerning socioecological theories to inform the development of precise care intervention plans.

Methods

Study design and participants

This study had a cross-sectional research design. The convenience sampling method was used to select CD patients who attended a gastroenterology treatment center in a tertiary-level A hospital in Nanjing city from August to November 2024.

The inclusion criteria were as follows: (1) Age ≥ 18 years; (2) Meet the diagnostic criteria for CD in the Consensus Opinion on the Diagnosis and Treatment of Inflammatory Bowel Disease (Beijing 2018) [1]; and (3) Primary school education and above, and be able to understand the questionnaire correctly.

The exclusion criteria were as follows: (1) Patients with mental illness or taking psychotropic drugs; and (2) Patients with severe comorbidities, such as organ insufficiency or malignant tumors.

Sample size of the study

According to *Kendal's* [24] sample size estimation method, the sample size is 5–10 times the number of variables. The total number of variable factors in this study is 24. The sample size should be between 120 and 240 cases, and the sample size of the included cases should be at least 144 cases or more, accounting for 20% of invalid questionnaires. To ensure the accuracy of the model and test its efficacy [25], 250 CD patients were ultimately included.

Ethical considerations and consent to participate

This study followed the Declaration of Helsinki and was approved by the ethics committee of Nanjing Second Hospital *(No. 2023-LS-Ky-022).* All study subjects gave informed consent and voluntarily participated in this study. In addition, this study was an anonymous survey, did not involve unethical behavior, and did not cause adverse health consequences to the participants' physical or mental health.

Measures

General information questionnaire

A self-designed general information questionnaire was used to collect data on sociodemographics and disease characteristics.

CD-CNS

The CD-CNS was used to assess the needs of patients. This scale was developed by Chen [15] in 2024 to assess the care needs of patients with CD. The scale consists of 27 items in five dimensions: medical needs (6 items), information needs (5 items), physical needs (7 items), psychological needs (5 items), and external support needs (4 items). Responses were rated on a 5-point Likert response scale (1 = not applicable, 2 = satisfied, 3 = low need, 4 = moderate need, and 5 = high need). The overall Cronbach's alpha coefficient for the CD-CNS was 0.940 [15]. The Cronbach's alpha for this scale in this study was 0.939.

Inflammatory bowel disease (IBD) patient symptom clusters assessment scale

This scale was used to assess symptom burden in patients with CD. The scale was developed by Gu [26] in 2020 to assess the symptoms of patients with CD. The scale consists of five dimensions, namely, the abdominal symptom cluster (3 items), intestinal symptom cluster (5 items), nutritional symptom cluster (3 items), systemic symptom cluster (4 items), and psychiatric-psychological symptom cluster (3 items), for a total of 18 entries, in which each of the entries includes 3 modules of frequency of occurrence, severity, and degree of distress and is based on a 5-point Likert scale according to the symptoms of patients with IBD. When the score ranges from 1 to 5, the higher the score is, the more severe the symptoms of IBD patients. The total Cronbach's alpha coefficient for this scale was 0.856 [26]. The Cronbach's alpha in this study was 0.883.

Family adaptability and cohesion scales, second edition (FACES II)

The FACES II was used to assess patients' family function. The scale was developed by Oison et al. [27]. And translated and validated in Chinese by Fei et al. [28]. The scale consists of 30 items, including 2 subscales of cohesion (16 items) and adaptability (14 items). The scale is scored on a 5-point Likert scale ranging from 1 to 5, from "not" to "always"; the higher the score is, the better the family cohesion and adaptability. The Cronbach's alpha coefficients for the FACES II ranged from 0.68 to 0.85 [28]. The Cronbach's alpha of this scale in this study was 0.895.

Post-traumatic growth inventory (PTGI)

The PTGI was used to assess *post-traumatic growth (PTG)* in patients. The scale was developed by Tedeschi [29] and translated and validated in Chinese by Wang [30]. The scale includes five dimensions—life perception, personal strength, new possibilities, relationships with others, and self-transformation—with 20 items, each of which is scored on a 6-point Likert scale, with 0, 1, 2, 3, 4, and 5 representing not at all, very little, few, some, many, and very much, respectively, and a total score of 100 points; higher scores indicate higher levels of PTG. The overall Cronbach's alpha coefficient for the PTGI is 0.874 [30]. The Cronbach's alpha for this scale in this study was 0.966.

Harvey-Bradshaw index (HBI)

IBD disease activity was assessed via the Harvey-Bradshaw Index in patients with Crohn's disease with HBI scores > 5, which is considered an active disease [31]. This scoring system consists of five items: general condition, abdominal pain, abdominal mass, diarrhea, and concomitant symptoms.

Data collection

The questionnaire for this study was distributed and collected by the researcher. Before the survey, patients were informed of the purpose and significance of the study and the requirements for questionnaire completion via uniform instructions, and an informed consent form was signed by the patients after their consent was obtained. During the survey, the questionnaire was filled out independently by the patients, and when the patients had questions about the questionnaire expression, the researcher answered them via a unified statement. After the survey, the paper questionnaires were collected on-site. After collection, two researchers performed a rigorous screening to exclude any questionnaires that contained logical errors, patterned responses, or incomplete fields.

Data analysis

In the first step, this study employed SPSS 27.0 for descriptive data analysis and a common method bias test. Qualitative data are described using *n* (%). The quantitative data obey the normal distribution by (x ± s), and the non-normal distribution by M (Q1, Q3).

In the second step, Mplus 8.3 was used for LPA. The fit indicators included (1) the *Akaike information criterion (AIC)*, *Bayesian information criterion (BIC)*, and *sample size-adjusted BIC (aBIC)*, with smaller values. A smaller value corresponds to a better model fit. (2) A closer *entropy* to 1 indicates that the model classification is more accurate when entropy ≧ 0.8, which indicates that the classification accuracy is greater than 90%. (3) *The Lo–Mendell–Rubin (LMR)* and *bootstrap likelihood ratio test (BLRT)* results when $P < 0.05$ indicate that the k - class model fits better than the k – 1 class model [32].

The third step is to compare qualitative data between groups by the χ^2 test, for quantitative data with non-normal distribution, pairwise comparisons between multiple groups of data were performed by the *Kruskal-Wallis test* and *Bonferroni correction*.

Finally, multivariate logistic regression analysis was used to analyze the influencing factors of profile categories, with profile categories as dependent variables, meaningful categorical variables in univariate analysis as factors, and continuous variables as covariates. The difference was statistically significant with $P < 0.05$. To make the multivariate analysis results more intuitive, we constructed the forest plot using *R version 4.3. 3*.

Results

Care needs scale scores of CD patients, sociodemographic characteristics, and disease information

A total of 259 questionnaires were distributed and returned in this study, 9 invalid questionnaires were excluded, and the recovery rate of valid questionnaires was 96.5%. The total CD-CNS score was (74.28 ± 23.96), which included medical needs (18.54 ± 6.69), information needs (17.46 ± 5.62), physical needs (18.04 ± 7.69), psychological needs (9.71 ± 5.39), and external support needs (10.54 ± 5.28). In this survey, the ages of 250 patients with CD ranged from 18 to 73 years, with a mean age of 36.60 ± 12.08 years. Of these, the majority (64.4%) were under 40 years of age, 71.2% of the patients had high a school education level or above, most of the patients (61.6%) were male, more than half (50.4%) were currently unemployed, most (67.2%) had CD intestinal surgery, more than half (80%) were treated with biological agents, 36% were in the active disease stage, and 51.6% needed gastrointestinal nutritional support. Baseline characteristics of patients with CD are presented in Table 1.

Results of the common method bias test

This study was self-reported by patients, which may lead to common method bias. The common method bias test was performed via the *Harman one-way method*, and the results revealed that there were 20 factors with eigenvalues > 1 and that the variance contribution rate of the first factor was 30.876% (< 40% of the recommended standard), suggesting that there was no serious common method bias, which indicates that the observed variable relationship can reflect the real theoretical correlation, and the variation of data is not the systematic bias caused by the measurement method itself.

Results of LPA of CD patients' care needs

In this study, the five dimensions of the CD-CNS were used as exogenous variables, and the number of model classes was increased sequentially starting from a single-class model to obtain the model of latent profiles from 1 to 5 classes; the fitting results are shown in Table 2. With the increase in the number of model classes, the values of Log L, AIC, BIC, and aBIC decreased continuously, but when the number of classes was 3, the entropy was greater; the difference was statistically significant, with $P < 0.01$ for LMR and BLRT. Whereas the BLRT and LMR for the category 4 and 5 models showed non-significant *p*-values ($P > 0.05$) and did not provide statistically better fits, the entropy for the category 3 (0.082) model was greater than that for category 2 (0.868), suggesting that the category 3 categorization was more accurate. In a comprehensive comparison, the category 3 model was identified as the best latent profile model in this study. In addition, the average probabilities of class attribution of the category 3 model were 95.6%, 93.0%, and 95.7%, suggesting that the accuracy of category attribution was high and that the results were credible.

Based on the model determination, the mean values of each category on the 5 dimensions of CD-CNS were plotted to create a distribution of category features in Fig. 1, and the 3 classes were named according to the fluctuations in the mean values of the entry scores. Class 1 mainly comprises patients in remission (93.8%). The CD-CNS score is (50.77 ± 10.93) points. The average score of each item is 1.5 to 2.3 points. The score is low, indicating that this type of patient can adapt to the physiological, psychological, social, and other effects of the disease, so it is named the "low-care-needs-adaptation group". The CD-CNS score of the Class 2 is (77.68 ± 12.98) points. Although the physiological needs score is higher than that of Class 1, the psychological needs are

Table 1 Descriptive statistics for sociodemographic and disease information ($n = 250$)

Variables	Categories	Frequency (n)	Proportion (%)
Duration of illness (years)	< 1	36	14.4
	1–5	93	37.2
	>5	121	48.4
Gender	Male	154	61.6
	Female	96	38.4
Age (years)	18–40	161	64.4
	41–59	77	30.8
	≥ 60	12	4.8
Marital status	Married	146	58.4
	Unmarried	99	39.6
	Divorcee	5	2.0
Fertility	No	111	44.4
	Yes	139	55.6
Educational background	Secondary schools	25	10.0
	Junior high school	47	18.8
	High school or junior college	101	40.4
	Undergraduate	68	27.2
	Postgraduate and above	9	3.6
Residence	Village	115	46.0
	Town	135	54.0
Type of medical payment	Self-pay	10	4.0
	Medical insurance	240	96.0
Current working status	Full-time	92	36.8
	Part-time	14	5.6
	Sick leave	18	7.2
	Unemployed	126	50.4
Monthly household income (CNY)	≤ 3000	39	15.6
	3001–6000	105	42.0
	6001–10,000	67	26.8
	>10,000	39	15.6
Annual expenditure on illness (CNY)	≤ 5000	10	4.0
	5001–10,000	25	10.0
	>10,000	215	86.0
Caregiver	Parents	99	39.6
	Spouse	72	28.8
	Children	14	5.6
	Self	57	22.8
	Parents and spouse	8	3.2
Current disease status	Acute episode	90	36.0
	Remission	160	64.0
Status of use of biological agents	Yes	200	80.0
	No	50	20.0
Purpose of admission	Medication	86	34.4
	Surgeries	50	20.0
	Rechecking	114	45.6
CD surgery	Yes	168	67.2
	No	82	32.8
Any complications	Yes	81	32.4
	No	169	67.6
Nasal feeding tube	Yes	77	30.8
	No	173	69.2
Stoma	Yes	27	10.8
	No	223	89.2

Table 1 (continued)

Variables	Categories	Frequency (*n*)	Proportion (%)
Abdominal drainage tube	Yes	23	9.2
	No	227	90.8
Current diet	Normal diet	95	38.0
	Restrictive diet	26	10.4
	Total gastrointestinal nutrition	80	32.0
	Supplementary gastrointestinal nutrition	49	19.6

Table 2 Potential classes of care needs among patients with CD

Class	Log (L)	AIC	BIC	aBIC	Entropy	LMR (*P*)	BLRT (*P*)	Categorical probability
1	-4026.118	8072.236	8107.451	8075.750	-	-	-	1
2	-3818.671	7669.342	7725.686	7674.964	0.868	0.000	0.000	0.556/0.444
3	-3745.949	7535.398	7613.371	7543.629	0.882	0.000	0.000	0.384/0.324/0.292
4	-3721.778	7499.557	7598.158	7509.395	0.894	0.0775	0.000	0.360/0.300/0.232/0.108
5	-3687.889	7443.777	7563.507	7455.724	0.926	0.0860	0.000	0.296/0.124/0.272/0.200/0.108

Note: Log (L) Log Likelihood, AIC Akaike information criterion, BIC Bayesian information criterion, ABIC adjusted BIC, LMR Lo–Mendell–Rubin, BLRT bootstrap likelihood ratio test

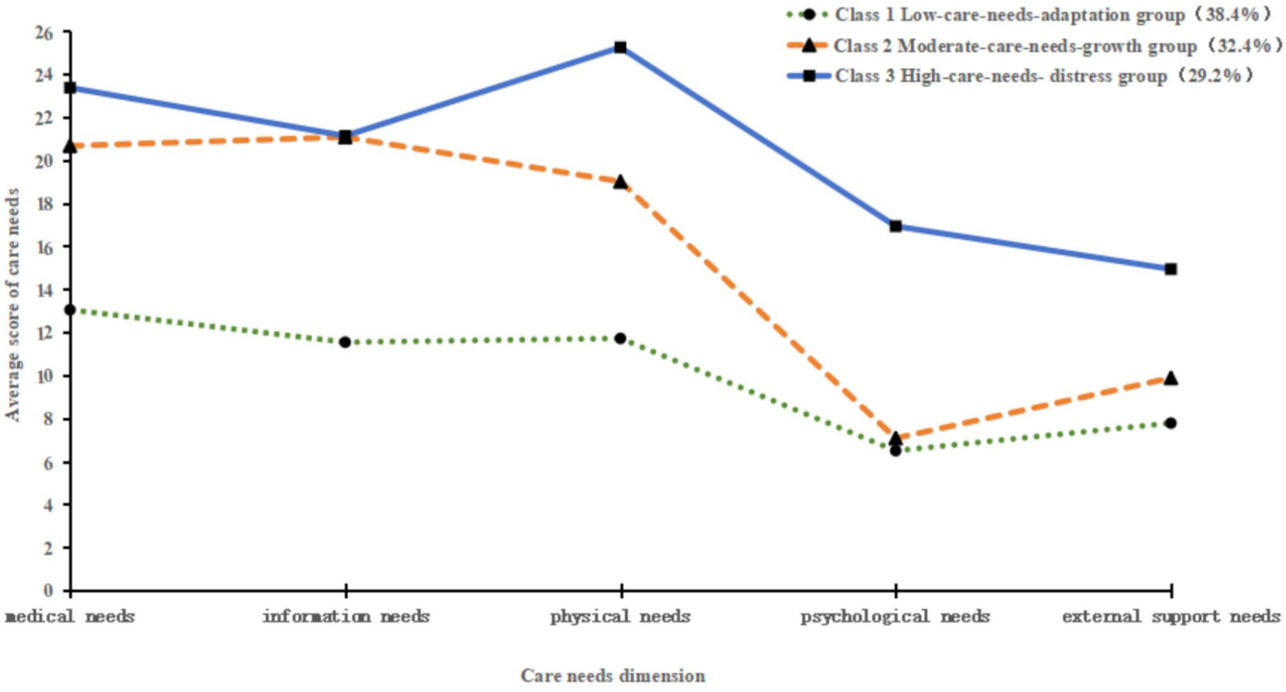

Fig. 1 The characteristic distribution of 3 potential classes of care needs among patients with CD

similar to those of C1, so it is named the "moderate-care-needs-growth group". The CD-CNS score of Class 3 was (101.44 ± 11.95) points, of which 69.9% were in the active phase and 23.3% of patients had a stoma, reflecting multidimensional distress; Moreover, these patients have high needs scores in five dimensions, especially the physical and psychological needs are significantly higher than other categories, so they are named "high-care-needs-distress group".

Univariate analysis of potential profile classes of care needs of CD patients

The results of the univariate analysis showed that the care needs of the 3 classes of patients were statistically significant ($P < 0.05$) in terms of monthly household income ($\chi^2 = 12.993$, $P = 0.043$), current work status ($\chi^2 = 18.583$, $P = 0.004$), disease status ($\chi^2 = 74.520$, $P < 0.01$), the purpose of admission ($\chi^2 = 30.676$, $P < 0.01$), complications ($\chi^2 = 11.503$, $P < 0.01$), nasal feeding tube ($\chi^2 = 27.318$, $P < 0.01$), stoma ($\chi^2 = 16.733$, $P < 0.01$) and current diet ($\chi^2 = 35.080$, $P < 0.01$). At the same time, compared with classes 1 and 2, patients in class 3 are more likely to be unemployed or frequently take sick leave, have lower monthly household income, and are more likely to have active disease, complications, stoma, and need nutritional support, as shown in Table 3.

The differences in the IBD symptom clusters assessment scale scores for Class 1, Class 2, and Class 3 were statistically significant ($P < 0.05$), and the differences in abdominal were not statistically significant except for Class 2 and Class 3 ($P > 0.05$), the rest were statistically significant; In intestinal, except for Class 1 and Class 2, the difference was not statistically significant ($P > 0.05$), and the rest were statistically significant; the differences in the scores of whole body, nutritional, psychosomatic, and other dimensions were statistically significant ($P < 0.05$). The differences in the family cohesion and adaptation scale scores of Class 1, Class 2, and Class 3 were statistically significant ($P < 0.05$). Among them, the scores of family cohesion, family adaptation, and other dimensions were statistically significant ($P < 0.05$). The differences in PTG scale scores Class 1, Class 2, and Class 3 were statistically significant ($P < 0.05$), among which the scores of life lessons, personal power, new possibilities, relationships with others, self-transformation, and other dimensions were statistically significant ($P < 0.05$), as shown in Table 4.

Results of multifactorial analysis of latent profile classes of care needs of CD patients

Multiple logistic regression analysis was performed with the latent profile classes of care needs of CD patients as the dependent variable and the variables that were statistically significant in the univariate analysis as the independent variables. The results of multivariate logistic regression analysis showed that: ① Comparison of the C1 and C3 groups, patients with disease activity, high symptom burden, poor family function, and low PTG were easily classified into the C3 group. Among them, the probability of active patients belonging to group C3 was higher than that in remission ($OR = 0.130$, $P = 0.029$); Patients with higher symptom burden had a higher probability of belonging to group C3 than patients with lower symptom burden ($OR = 0.948$, $P < 0.01$); Patients with poor family function had a higher probability of belonging to group C3 than patients with good family function ($OR = 1.108$, $P < 0.01$); Patients with low PTG had a higher probability of belonging to group C3 than patients with high PTG ($OR = 1.042$, $P = 0.018$). ② Comparison of the C2 and C3 groups, patients with no stoma, low symptom burden, good family function, and high PTG were easily classified into group C2. Among them, patients without stoma had a higher probability of belonging to group C2 than patients with stoma ($OR = 0.232$, $P = 0.025$); Patients with lower symptom burden had a higher probability of belonging to group C2 than patients with higher symptom burden ($OR = 0.971$, $P < 0.01$); Patients with good family functioning had a higher probability of belonging to group C2 than patients with poor family functioning ($OR = 1.057$, $P = 0.016$); Patients with high PTG had a higher probability of belonging to group C2 than patients with low PTG ($OR = 1.032$, $P = 0.027$). ③ Comparison of the C1 and C2 groups, patients with low symptom burden, good family function, and disease in remission were easily classified into the C1 group. Among them, patients in remission had a higher probability of belonging to group C1 than in the active phase ($OR = 6.804$, $P = 0.022$); Patients with lower symptom burden had higher probability of belonging to group C1 than patients with higher symptom burden ($OR = 1.025$, $P = 0.023$); Patients with good family functioning had a higher probability of belonging to group C1 than patients with poor family functioning ($OR = 0.954$, $P = 0.01$), See Table 5. To intuitively see the influencing factors of different potential classes of care needs, we added a forest diagram for visualization. See Figs. 2 and 3, **and** Fig. 4.

Discussion

There is heterogeneity in the care needs of CD patients, and we need to pay attention to the high-care-needs-distress group

The results of this study show that the care needs of CD patients can be divided into three potential classes: the "low-care-needs-adaptation group", the "moderate-care-needs-growth group" and the "high-care-needs-distress group", suggesting that there is a pronounced heterogeneity in the care needs of CD patients, which further supplements the previous study [33–34] that the care needs of CD patients are regarded as a homogeneous whole, can better meet the differentiated needs of patients, and provide guidance for the formulation of targeted interventions in further research.

The high-care-needs-distress group accounted for 29.2% (73/250) of all CD patients, and patients in this class scored higher than the overall level on all CD-CNS dimensions. The reasons for this are as follows: (1) Patients are in the active stage of the disease and are in urgent need of medical support in the face of changes in their condition. (2) The high cost of medication and the risk of surgery creates some subjective and objective economic toxicity for patients and their families [6]. (3) Changes in self-image caused by changes in intestinal function and the uncertainty of treatment aggravate the psychological burden of patients [7]. According to *Maslow's hierarchy of needs theory*, somatic function is the prerequisite for safeguarding physiological needs and the basis for realizing higher-level needs [35], which suggests that healthcare professionals need to focus on this group of patients, encourage active participation in

Table 3 Univariate analysis of potential classes of care needs among **patients with CD**

Variables	Categories	Class 1	Class 2	Class 3	χ^2	*P*
Duration of illness (years)	< 1	11(11. 4)	18(22. 2)	7(9. 6)	7. 435	0. 115
	1–5	40(41.7)	28(34. 6)	25(34. 2)		
	>5	45(46. 9)	35(43. 2)	41(56. 2)		
Gender	Male	65(67. 7)	47(42. 0)	42(57. 5)	2. 462	0. 292
	Female	31(32. 3)	34(58. 0)	31(42. 5)		
Age (years)	18–40	64(66. 7)	52(64. 2)	45(61. 6)	1. 609[a]	0. 822
	41–59	26(27.1)	26(32.1)	25(34.3)		
	≥ 60	6(6. 2)	3(3. 7)	3(4. 1)		
Marital status	Married	53(55. 2)	48(59. 3)	45(61. 6)	4.137[a]	0.378
	Unmarried	41(42. 7)	33(40. 7)	25(34. 3)		
	Divorcee	2(2. 1)	0(0. 0)	3(4. 1)		
Fertility	No	48(50. 0)	35(43. 2)	28(38. 4)	2. 346	0. 309
	Yes	48(50. 0)	46(56. 8)	45(61. 6)		
Educational background	Secondary schools	8(8. 3)	10(12. 3)	7(9. 6)	10. 197[a]	0. 239
	Junior high school	23(24. 0)	11(13.6)	13(17. 8)		
	High school or junior college	44(45. 8)	29(35. 8)	28(38. 3)		
	Undergraduate	20(20. 8)	27(33. 4)	21(28. 8)		
	Postgraduate and above	1(1. 1)	4(4. 9)	4(5. 5)		
Residence	Village	49(51. 0)	33(40. 7)	33(45. 2)	1. 903	0. 386
	Town	47(49. 0)	48(59. 3)	40(54. 8)		
Type of medical payment	Self-pay	5(5.2)	4(4.9)	1(1.4)	1. 886	0. 393
	Medical insurance	91(94. 8)	77(95. 1)	72(98.6)		
Current working status	Full-time	49(51. 0)	27(33. 3)	16(21. 9)	18. 583[a]	0. 004
	Part-time	5(5. 2)	6(7. 4)	3(4. 2)		
	Sick leave	5(5.2)	8(9. 9)	5(6. 8)		
	Unemployed	37(38. 6)	40(49. 4)	49(67. 1)		
Monthly household income (CNY)	≤ 3000	10(10. 4)	9(11. 1)	20(27. 4)	12. 993	0. 043
	3001–6000	45(46. 9)	33(40. 7)	27(37. 0)		
	6001–10,000	25(26. 0)	23(28. 4)	19(26. 0)		
	>10,000	16(16. 7)	16(19. 8)	7(9. 6)		
Annual expenditure on illness (CNY)	≤ 5000	4(4. 2)	5(6. 2)	1(1. 4)	6. 254[a]	0. 172
	5001–10,000	14(14. 6)	7(8. 6)	4(5. 5)		
	>10,000	78(81. 2)	69(85. 2)	68(93. 1)		
Caregiver	Parents	37(38. 5)	29(35. 8)	33(45. 3)	4.465[a]	0.825
	Spouse	26(27. 1)	27(33. 4)	19(26. 0)		
	Children	5(5. 2)	4(4. 9)	5(6. 8)		
	Self	26(27. 1)	18(22. 2)	13(17. 8)		
	Parents and spouse	2(2.1)	3(3.7)	3(4. 1)		
Current disease status	Acute episode	6(6. 2)	36(44. 4)	51(69. 9)	74.520	< 0.01
	Remission	90(93. 8)	45(55. 6)	22(30. 1)		
Status of use of biological agents	Yes	81(84. 4)	63(77. 8)	56(76. 7)	1. 892	0. 388
	No	15(15. 6)	18(22. 2)	17(23. 3)		
Purpose of admission	Medication	31(32. 3)	30(37. 0)	25(34. 2)	30. 676	< 0.01
	Surgeries	5(5. 2)	19(23. 5)	26(35. 6)		
	Rechecking	60(62. 5)	32(39. 5)	22(30. 2)		
CD surgery	Yes	68(70. 8)	53(65. 4)	47(64. 4)	0. 953	0. 621
	No	28(29. 2)	28(34. 6)	26(35. 6)		
Any complications	Yes	20(20. 8)	28(34. 6)	33(45. 2)	11. 503	0. 003
	No	76(79. 2)	53(65. 4)	40(54. 8)		
Nasal feeding tube	Yes	14(14. 6)	25(30. 9)	38(52. 1)	27. 318	< 0.01
	No	82(85. 4)	56(69.1)	35(47. 9)		
Stoma	Yes	5(5. 2)	5(6. 2)	17(23. 3)	16. 733	< 0.01
	No	91(94. 8)	76(93. 8)	56(76. 7)		

Table 3 (continued)

Variables	Categories	Class 1	Class 2	Class 3	χ^2	*P*
Abdominal drainage tube	Yes	3(3. 1)	7(8. 6)	13(17. 8)	10. 747	0.050
	No	93(96. 9)	74(91. 4)	60(82. 2)		
Current diet	Normal diet	56(58. 3)	25(30. 9)	14(19. 2)	35. 080	< 0.01
	Restrictive diet	5(5. 2)	11(13. 6)	10(13. 7)		
	Total gastrointestinal nutrition	16(16. 7)	32(39. 5)	32(43. 8)		
	Supplementary gastrointestinal nutrition	19(19. 8)	13(16. 0)	17(23. 3)		

Note: "a" Fisher exact probability method

Table 4 Comparison of scores on different dimensions of the family cohesion, adaptation, PTG and IBD symptom cluster scale across the three different models

	Classification			LSD	H	*P*
	Class 1 (*n* = 96)	Class 2 (*n* = 81)	Class 3 (*n* = 73)			
Symptom cluster	69.00(60.00, 83.00)	93.00(72.00, 107.00)	111.00(93.00, 132.50)	C3> C2> C1	90.982	<0.01
Abdomen	15.00(12.00, 18.00)	19.00(15.50, 27.00)	22.00(18.00, 29.00)	C2> C1**, C3> C1**	60.740	<0.01
Intestinal	15.00(15.00, 18.00)	17.00(15.00, 21.00)	21.00(15.00, 30.00)	C3> C1**, C3> C2*	30.232	<0.01
Nutrition	12.00(9.00, 17.75)	18.00(12.00, 28.50)	27.00(18.00, 31.00)	C3> C2> C1	58.635	<0.01
Whole Body	14.50(12.00, 17.75)	15.00(2.00, 21.00)	20.00(15.00, 23.00)	C3> C2> C1	46.877	<0.01
Psychosomatic	10.00(9.00, 14.75)	12.00(9.00, 18.00)	21.00(15.00, 28.50)	C3> C2> C1	69.549	<0.01
Family	108.50(100.25,118.00)	98.00(89.50,105.00)	88.00(83.00, 93.00)	C1> C2> C3	94.266	<0.01
Cohesion	60.00(55.00, 67.00)	54.00(48.00, 58.50)	48.00(45.00, 50.50)	C1> C2> C3	88.508	<0.01
Adaptation	48.00(45.00, 52.00)	44.00(41.00, 47.50)	41.00(37.50, 43.00)	C1> C2> C3	75.424	<0.01
PTG	70.00(59.00, 79.75)	60.00(44.00,70.50)	38.00(23.00, 49.00)	C1> C2> C3	92.775	<0.01
Life Lessons	24.00(19.25, 27.00)	20.00(14.50, 24.00)	13.00(7.00, 17.00)	C1> C2> C3	94.743	<0.01
Personal Power	12.00(10.00, 14.00)	9.00(8.00, 12.00)	7.00(4.00, 9.00)	C1> C2> C3	88.717	<0.01
New possibilities	12.00(9.00, 13.00)	9.00(5.00, 12.00)	4.00(2.00, 8.00)	C1> C2> C3	73.953	<0.01
Relationships with Others	10.00(9.00, 11.75)	9.00(6.00, 10.00)	5.00(2.00, 7.00)	C1> C2> C3	77.339	<0.01
Self-Transformation	14.00(11.25, 16.00)	12.00(8.50, 14.00)	9.00(7.00, 10.00)	C1> C2> C3	63.260	<0.01

$^{*}p < 0.05$, $^{**}p < 0.01$, " *p* " The *p*-value after Bonferroni correction

Table 5 Results of the multivariate logistic analysis of the factors influencing latent profiles associated with care needs in patients with CD

	Variables	β	S.E.	waldχ^2	*P*	OR	95% CI
Class 1 versus Class 3[a]	Acute episode	-2.038	0.934	4.763	0.029*	0.130	[0.021, 0.812]
	Stoma	-0.636	0.926	0.472	0.492	0.529	[0.086, 3.251]
	Symptom burden	-0.054	0.012	18.509	<0.01**	0.948	[0.925, 0.971]
	family function	0.102	0.026	15.576	<0.01**	1.108	[1.053, 1.165]
	PTG	0.042	0.018	5.559	0.018*	1.042	[1.007, 1.079]
Class 2 versus Class 3[a]	Acute episode	-0.120	0.620	0.038	0.846	0.887	[0.263, 2.990]
	Stoma	-1.461	0.652	5.025	0.025*	0.232	[0.065, 0.832]
	Symptom burden	-0.029	0.009	11.495	<0.0^{1**}	0.971	[0.955, 0.988]
	family function	0.055	0.023	5.781	0.016*	1.057	[1.010, 1.105]
	PTG	0.032	0.014	4.898	0.027*	1.032	[1.004, 1.062]
Class 2 versus Class 1[b]	Acute episode	1.918	0.837	5.253	0.022*	6.804	[1.320,35.070]
	Stoma	-0.825	0.917	0.810	0.368	0.438	[0.073, 2.643]
	Symptom burden	0.024	0.011	5.146	0.023*	1.025	[1.003, 1.047]
	family function	-0.047	0.018	6.718	0.010*	0.954	[0.921, 0.989]
	PTG	-0.010	0,014	0.483	0.487	0.990	[0.963, 1.018]

Note: Class1 is the low-care-need-adaptation group, Class 2 is the moderate-care-needs-growth group, and Class 3 is the high-care-need-distress group. "a" Class 3 is the reference group; " b " Class 1 is the reference group. $^{*}p < 0.05$, $^{**}p < 0.01$

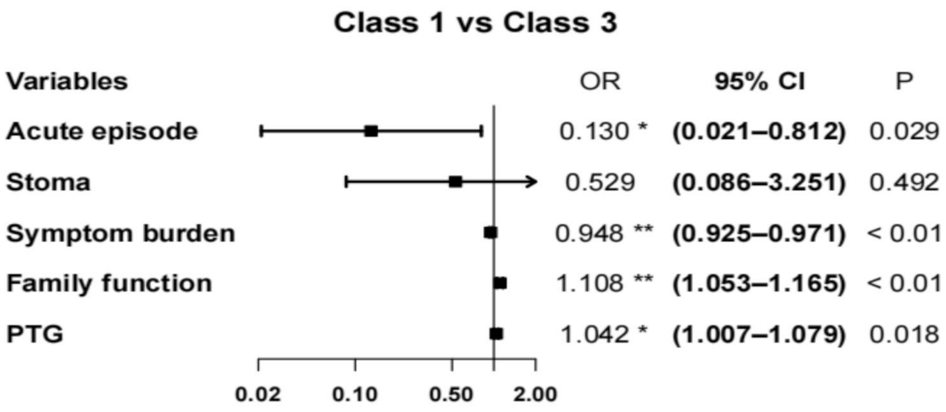

Fig. 2 Comparison of the results of multivariate analysis of Class 1 and Class 3 care needs

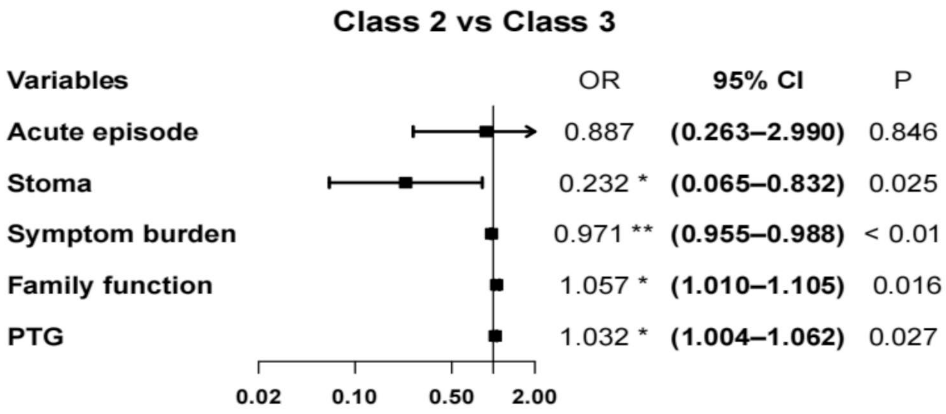

Fig. 3 Comparison of the results of multivariate analysis of Class 2 and Class 3 care needs

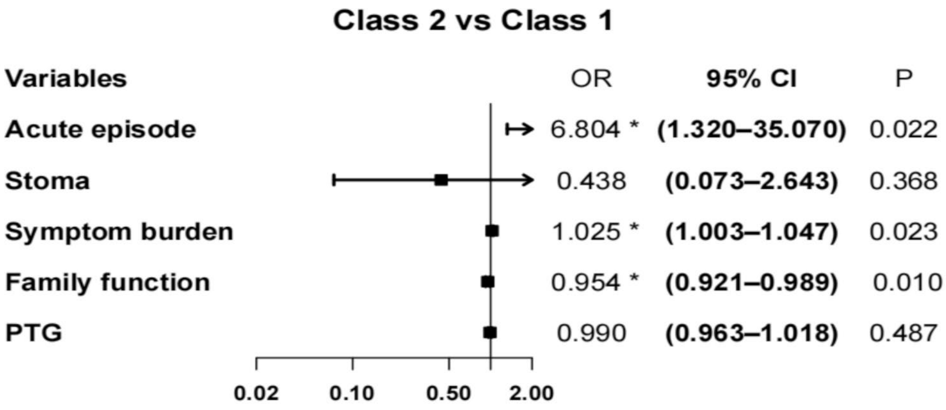

Fig. 4 Comparison of the results of multivariate analysis of Class 2 and Class 1 care needs

treatment, strengthen symptom management, and guide them to seek management experience from patients who have better control of their diseases.

The moderate-care-needs-growth group accounted for 32.4% (81/250) of all CD patients, and patients in this class scored higher in information needs and lower in psychological needs. This suggests that patients in this class always remain hopeful in the face of disease distress and are eager to seek health information related to disease self-management, wanting to promote disease recovery through positive lifestyle adjustments. *Health information needs* refer to the needs of patients who are in a particular time or situation and recognize that the information they obtain is insufficient to achieve a goal [36]. Adequate information can reduce patients' disease-related concerns [37]. The *Healthy China 2030*

Planning Outline explicitly proposes the promotion of *Internet + Healthcare services* to meet the needs of patients for personalized services and precision medicine [38]. These findings suggest that healthcare professionals can use Internet healthcare to provide patients with professional and targeted care services such as symptom monitoring, medication, diet, emotion, exercise, etc. A study [39] has demonstrated that a feedback-based health education model based on a cloud platform imparting knowledge of self-management of IBD patients, remote monitoring of disease symptoms, and guidance meets the needs of patients and improves their self-management skills.

The low-care-needs-adaptation group accounted for 38.4% (96/250) of all CD patients, and the lower scores of this class of patients on the dimensions of the CD-CNS may be related to the fact that this class of patients is in remission, with a lower burden of symptoms and a higher level of family function and psychology. This suggests that patients in this category can correctly understand their disease and actively adapt to the changes in their lives brought about by the disease; at the same time, the patient's family members can provide the attentive care and financial and emotional support they need. Although the needs of this group of patients are low, the disease is long-lasting with recurrent episodes, so healthcare professionals still need to warn patients of the importance of long-term self-management and change the traditional misconception of "slow disease, slow treatment" to maintain a long-term low level of need.

Analysis of factors influencing different classes of care needs of CD patients

Differences in the characteristics of different classes of diseases

Disease active phase The results of this study revealed that patients in the active phase were more likely to belong to the high-care-needs-distress group than those in the other two groups. This may be because, during the onset of the disease, the aggravation of symptoms can lead to sudden impairment of the patient's physical function, which not only hurts the patient's daily life and psychology but also increases the difficulty of treatment and the economic burden [40]. These findings suggest that healthcare professionals need to assess patients' acceptance of symptoms promptly during the active period and provide appropriate interventions to promote disease relief and enable them to resume normal work and life. Second, positive psychological guidance is offered to patients, and research [41] shows that the presence of severe symptoms prompts patients to change their health behaviors. Patients realize that the present is a good time for symptom management, prompting them to set their mindset right and actively engage in disease management. In addition, single-disciplinary care makes it difficult to cope with the multiple needs CD patients face during the active period. With the progress of medical research, *multidisciplinary combined therapy* is gradually becoming a key direction of disease management. Taylor [42] used a *nurse-led multidisciplinary nursing model*, in which nurses and general practitioners provided personalized supportive care, and the unmet needs of lymphoma patients were reduced. Therefore, it can be applied to CD patients to alleviate negative emotions during the period and meet their diverse care needs during the active period.

Stomas The results of this study showed that patients with stoma were more likely to belong to the high-care-needs-distress group than patients in the moderate-care-needs-growth group. Patients with stomas may suffer from disturbances in body image due to changes in body shape, and some of them may even suffer from psychological problems such as a sense of shame and a decrease in self-confidence [43]. Therefore, CD patients with stomas should be instructed to adopt appropriate self-emotion regulation methods, such as acceptance and commitment therapy, which is a psychotherapeutic model pioneered based on cognitive behavioral therapy, and its role in helping patients to enhance their positive emotions has been verified in the domestic IBD group, through which stoma patients can be helped to determine the meaning of life, improve their negative emotions, and enhance their self-identity [44].

Relationships between symptom burden and the care needs of CD patients

The results revealed differences in the level of symptom burden among the three groups of CD patients, with patients with greater symptom burdens being more likely to belong to the high-care-needs-distress group. This is similar to the findings of Wang [45]. These patients not only have gastrointestinal symptoms of diarrhea and abdominal pain due to the disease itself [46]. They may also be accompanied by systemic symptoms such as fatigue, sleep disturbances, weight loss, and psychological symptoms such as anxiety and depression [47]. Studies [48] have shown that although symptoms are particularly severe for patients during exacerbations, patients in remission are not completely symptom-free, and these symptoms can directly or indirectly affect the optimal management of the disease and quality of life. Therefore, healthcare professionals need to assess the frequency and severity of patients' symptoms dynamically and develop patient-centered symptom management plans in terms of remission-phase symptom prevention, such as changes in diet, work and rest, and exercise, respectively, and active-phase symptom coping, such as active medical treatment, to reduce the symptom burden on patients and improve their quality of life. Secondly, symptom management for CD patients is a long-term process. Therefore, it is recommended that healthcare organizations combine with communities and families to build a *tripartite support system* for patient data sharing, communication, and interaction to meet the ongoing symptom management needs of CD patients [49].

Relationships between family function and the care needs of CD patients

The results of this study revealed differences in the levels of family cohesion and adaptability among the three groups of CD patients, and patients with better family cohesion and adaptability were more likely to belong to the low-care-needs-adaptation group, which is similar to the findings of Qin [50]. Because the family function is the ability of the family as a whole to meet the needs of its members, the better the family function is, the more it can respect the patient's wishes in medical decision-making so that the patient can feel respected and be more objective in recognizing his or her physical condition, reducing inner turmoil, and accordingly reducing unmet needs [50]. Second, home enteral nutrition support and dietary management are important for the development and prognosis of CD [51], and daily supervision and comanagement by family members can play a substantial role in the recovery of patients. In the high-care-needs-distress group, the family function was poor. This may be because young adults constitute the main group of individuals with this disease, who are in a rising period of academic, career, and family development, and patients in the period of severe disease activity have to take a break from school, frequently leave or even quit their jobs to cooperate with the treatment of the disease [52], and some families have difficulty adapting to this unexpected situation. Here, family adaptability can be understood as the family's ability to cope with the emergent situation [28]. In addition, although CD has been included in outpatient special diseases and outpatient chronic diseases in some regions of China, the reimbursement of medical insurance is limited, and long-term outpatient treatment and repeated hospitalization still bring serious financial pressure to families, which makes patients feel guilty and think that they are a burden on the family. Therefore, for this type of patient, it is recommended that caregivers focus on the patient's family and encourage family members to participate in disease management and diagnostic and therapeutic decision-making to promote the patient's perception of family intimacy and help him or her establish a good family support system. Second, they should take the initiative to understand the patient's financial pressure and inform the patient of the reimbursement rate of medical insurance and the channels of financial support that can be sought to improve the patient's financial situation. Finally, Zhao [53] has shown that family participation in psychological care also has significant effects on improving patient needs. Therefore, for patients with enterostomy and active CD, family members should be encouraged to give full play to the support function of the family system and actively participate in the patient's care work, and patients should be given more emotional support and value affirmation from the family to meet the patient's psychological and support needs and reduce guilt.

Relationships between PTG and the care needs of CD patients

Interestingly, the study found that patients with higher levels of PTG were more likely to belong to the low-care-needs-adaptation group and the moderate-care-needs-growth group ($P > 0.05$), with no significant difference between the two groups, consistent with the results of the profiling analysis. PTG is a positive psychological change experienced by individuals in the process of struggling with traumatic events [29] and can alleviate negative emotions and improve quality of life [54]. The higher scores in the moderate-care-needs-growth group may be because this group of patients experienced a positive psychological response to the illness, were able to cope positively even in a state of illness-induced discomfort, and were eager to seek information related to knowledge about the illness, diet, and exercise. Stress coping theory states that individuals fully mobilize internal and external resources through cognition and behavior to cope with stressful events [55]. Here, the desire to seek information support can be considered a form of coping that helps patients reappraise stressful events and discover internal and external resources to face illness with a positive attitude. This also demonstrates how illness or trauma can not only negatively affect an individual but also positively influence personal growth and health behaviors [56]. Secondly, patients with this type of CD may have achieved personal growth by relying on their own efforts and external support. They reflect on their experiences and learn to continuously adjust their internal understanding and sense of self, effectively "rebuilding themselves after the disease" [57]. As a result, these patients may have higher scores in PTG. For such individuals, clinical medical staff can utilize mobile information technology for patient management, such as offering professional and targeted disease management information through the IBD health education app network platform [58]. For the low-care needs-adaptation group, patients with higher levels of psychological function were more able to view the disease dialectically, reduce the negative impact of the disease through the internal and external environments, adapt to the disease, and adopt more health-promoting behaviors to manage the disease [59]. For the high-care-needs-adaptation group, the activity of the disease may cause trauma to the patient, which in turn will cause the patient to have symptoms of anxiety, depression, and fatigue and aggravate the patient's physical and psychological needs [23]. It is suggested that medical staff can help patients express their emotions through *narrative therapy*, such as story listening and positive response, to meet their psychological needs [60].

The complexity of sociological demographic variables

Although the demographic characteristics of CD patients are not easy to intervene with, understanding the inter-patient differences in different care needs categories can help healthcare workers identify high-care-need patients early. The results of the univariate analysis of this study showed that the proportion of patients with full-time employment in the high-care-needs distress group (22.0%) was significantly lower than that in the other two groups (51.0%, 33.3%), and the proportion of household monthly income ≤ 3000 was higher (27.4% vs. 11.1%, 10.4%). Combined with Yu's [6] research, economic vulnerability may exacerbate healthcare burden and anxiety levels, which in turn leads to higher demand. In addition, patients in this group received nasogastric feeding more frequently (51.2%), total enteral nutrition (43.8%), and complication rate (45.2%), which may lead to body image changes and may induce self-identity crisis, further increasing psychological burden [7]. Although these factors are not insignificant in multivariate models, their importance in univariate analyses remains alarming. In addition, univariate analysis showed no statistically significant difference in nursing needs between the three groups of patients in age and gender ($P > 0.05$). Possibly because heterogeneous sample stratification may weaken statistical power, the age-sex distribution in this study was consistent with the epidemiological characteristics of CD (<40 years 64.4%; males 61.6%) [4]. In addition, the results of this study are consistent with the view put forward by Mak [3] that "the high needs of young and middle-aged patients are mainly due to disease activity rather than age itself". In the future, the association of sociodemographic variables with care needs can be further explored through stratified sampling or expanded sample size.

Limitations

Despite the inclusion of this study from rural and urban areas of more than 40 districts in 11 provinces of China and the sample institution as an authoritative tertiary-level A hospital in China in the field of CD diagnosis and treatment, its patient population has a wide geographical coverage and diversity of demographic characteristics. However, the following limitations still need to be addressed. First, at the level of sampling method, given the very limited number of CD-specialized diagnostic and treatment institutions in China, the use of convenience sampling in this study may lead to sample structure bias, and it is suggested that stratified random sampling or probability sampling based on the regional healthcare institution registration system may be used in subsequent studies to enhance the extrapolation validity of the sample to the national CD patient population. Second, at the level of data collection, the assessment system based on subjective reports in this study may introduce social expectation bias and recall bias, and it is suggested that future studies may construct a comprehensive assessment model combining subjective and objective data to validate self-reported data by testing *fecal calreticulin levels* and *C-reactive protein* concentrations of validated biomarkers [61]. Furthermore, in terms of study design, cross-sectional studies limit the inference of causality, and it is suggested that prospective longitudinal study designs could be conducted in the future to systematically track the dynamic trajectory of the care needs of patients with CD at different stages. Meanwhile, collaborative multi-center studies can be conducted to effectively expand the sample size and enhance the reliability of results. Finally, at the tool application level, the validation of the CD-CNS scale is currently limited to the Chinese population. To enhance the cross-cultural adaptability of the assessment tool, it is suggested that future validation studies can be conducted in different healthcare systems and socio-cultural contexts, and cross-cultural comparisons can be carried out to enhance confidence in its use.

Conclusion

In summary, our findings have important implications for the management of patients with CD in the Chinese clinical setting. First, the study used LPA for the first time to explore the care needs of patients with CD, identifying three classes. Healthcare workers can develop individualized supportive care plans based on the characteristics of patients in different classes. Second, based on social-ecological system theory, this study analyzed the influencing factors of different classes at multiple levels and revealed that disease status, the presence of a stoma, symptom burden, family adaptability and cohesion, and PTG affect patients' care needs. In the future, it is recommended that clinical medical staff evaluate CD care needs in multiple dimensions and set up interdisciplinary teams to collaboratively manage diseases; At the same time, combined with the results of this study and incorporating CD-CNS into the outpatient routine process, a dynamic monitoring system of "periodic routine assessment + special assessment during active period" was constructed to more accurately capture the care needs of CD patients and ensure the accurate matching of nursing measures with the real-time needs of patients.

Abbreviations

CD	Crohn's disease
SCNS-SF34	34-item Supportive Care Needs Survey
CD-CNS	Crohn's Disease Care Needs Scale
LPA	Latent profile analysis
IBD	Inflammatory bowel disease
FACES II	Family Adaptability and Cohesion Scales, Second Edition
PTGI	Post-traumatic Growth Inventory
PTG	Post-traumatic growth
HBI	Harvey-Bradshaw Index
AIC	Akaike information criterion
BIC	Bayesian information criterion
aBIC	Sample size-adjusted BIC
LMR	Lo–Mendell–Rubin
BLRT	Bootstrap likelihood ratio test
Log L	Log Likelihood
CI	Confidence interval
OR	Odds ratio

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Author contributions

All authors contributed to the study conception and design. DRF: data collection, data analysis, first draft of thesis. MW: help with data analysis and thesis translation. LM, CDL, CY, PT: study design and conceptualization, manuscript revision. KF: clinical assistance and patient co-ordination.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

This study followed the Declaration of Helsinki and was approved by the ethics committee of Nanjing Second Hospital (No. 2023-LS-Ky-022). All study subjects gave informed consent and voluntarily participated in this study. In addition, this study was an anonymous survey, did not involve unethical behavior, and did not cause adverse health consequences to the participants' physical or mental health.

Consent for publication

Not applicable.

Informed consent

Informed consent was obtained from all individual participants included in the study.

Competing interests

The authors declare no competing interests.

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