

Application progress of shared decision-making in patients with inflammatory bowel disease

Limei Zou^{1,a,*}, Jinping Zhan¹, Jingshi Liao¹, Xiaolei Wang^{1,b,*}

¹School of Nursing, Hangzhou Normal University, Hangzhou, 310000, China

^a1282121959@qq.com, ^bwxlwmn@126.com

*Corresponding author

Abstract: The incidence of inflammatory bowel disease (IBD) is increasing year by year, especially in Asia, which has become one of the major challenges for global public health. The clinical strategy of inflammatory bowel disease is complex, and shared decision-making helps patients and health care providers to develop personalized treatment plans. This article mainly from the necessity of Shared decision making in inflammatory bowel disease treatment, nurses in the role, promote the sharing decision-making decision aid tool and the influence of Shared decision making in inflammatory bowel disease aspects were reviewed, in order to further pushed forward in inflammatory bowel disease Shared decision-making to provide theoretical reference.

Keywords: shared decision-making; Inflammatory bowel disease; Ulcerative colitis; Crohn's disease

1. Introduction

Inflammatory bowel disease (IBD) is a complication accumulation system more chronic gastrointestinal diseases, including Ulcerative colitis (UC) and Crohn's disease (GU). Number of cases of IBD in western countries for more than 0.3% of the population, the incidence of IBD continue to rise^[1], from 1990 to 2019, the standardized incidence of inflammatory bowel disease in our country from the rising of 1.47/10to 3.01/10^[2], due to its long duration, high morbidity, the high cost of treatment, cause serious burden to patients and the whole medical system.

Due to its long course of disease, high disability rate and high treatment cost, the pathogenesis of IBD is still unclear. With the continuous development of molecular biology, modern immunology and other disciplines, the research on the pathogenesis of IBD is deepening, and new treatment methods for IBD are^[3] increasing. Due to the complexity of medical decision-making in IBD, the treatment decisions of patients usually depend on doctors, but the differences in decision-making perspectives between doctors and patients lead to decision-making conflicts between doctors and patients. Since IBD patients require long-term or even lifelong treatment, the risks and benefits of different treatment decisions are also significantly different, so it is necessary for medical staff to incorporate the patient's personalized treatment needs into the decision-making process. shared decision making (SDM) is a collaborative process that improves patient engagement by sharing treatment information, incorporating patient values and treatment preferences, so that patients and health care providers make treatment decisions together. Previous research has shown^[4] that, Previous studies have shown that SDM can reduce patient decision-making conflicts and reduce healthcare costs. In view of the complexity of medical decision-making in IBD, shared decision-making provides a scientific solution for its decision-making. Therefore, this article reviews previous related research, in order to provide theoretical reference for this kind of patients to make medical decisions.

2. Concept of SDM

Shared decision^[5] making refers to the process of reducing information inequality between doctors and patients by continuously improving patients' cognition of diseases and treatment options in the absence of the "best" choice, and constantly exchanging information between doctors and patients to achieve consistent decision-making. SDM can improve patients' cognition of disease and treatment plan through knowledge sharing, and help patients choose the same nursing method as their own values and preferences. SDM in big difference on the applicability of the different disease types, SDM are best suited for treatment of a variety of choices, and these choices on the treatment effect, but the individual

may produce different effect of different (such as the cost of treatment, treatment of adverse reactions, etc.)^[6], many chronic diseases are belong to the category of applicable, For example, SDM significantly improves the medication compliance^[7] of asthma patients and optimizes the treatment effect^[8] of hospitalized patients with acute exacerbation of chronic obstructive pulmonary disease. SDM is no longer applicable when there is a clear standard of care for certain conditions or when the benefits of a treatment option clearly outweigh the risks: In clinical practice, this kind of disease is evidence-based medicine support and decision-making risk is relatively low, the difference between individual patients has little effect on the result of the treatment, the doctor may according to the best practices guide or professional consensus recommend specific treatment, the patient's participation may be less; In addition, SDM is generally applicable in emergency and emergency surgery situations, where doctors need to take immediate treatment measures to save the life of patients, and there is a lack of time^[9] to discuss in detail with patients and their families and guide them to choose treatment options. In recent years, SDM has been widely used in clinical practice by doctors and nurses abroad, and has good effects on treatment compliance and satisfaction. At present, SDM has been applied^[10-13] to different degrees in the fields of cancer, asthma, mental disorders, cardiovascular and cerebrovascular diseases, etc. In China, scholars Ma Lu^[14] applied SDM to patients with atrial fibrillation ablation, and Xia Chunjuan^[15] applied it to primiparas with vaginal delivery. Although patients for participation in China's enthusiasm high, but because of the SDM research started relatively late, the majority of patients didn't really involved in the decision-making process. Studies^[16] have shown that about 80% of IBD patients in China want to be involved in decision-making, but in fact only about half of IBD patients express their treatment preferences in the decision-making process.

3. The necessity of shared decision-making in patients with inflammatory bowel disease

3.1. The complexity of treatment decisions in patients with IBD

IBD is a complex chronic progressive disease that includes two forms: ulcerative colitis (UC) and Crohn's disease (CD). At present, the clinical management strategy of IBD is stratified according to the severity. Patients with mild to moderate IBD are generally treated with aminosalicylic acid, hormones and other drugs. Refractory patients with severe complications (perforation, tumor, etc.) are suitable for surgical treatment^[17]. Diversified treatment is good for treating diseases, but produced the risks and benefits of treatment, and the existing evidence to show that what kind of treatment is the best choice, to patients on the choice of treatment decisions can be difficult. With the advent of new drugs and new treatment modalities, treatment decisions will become more complex.

3.2. Differences in treatment decisions

Patient preferences are influenced by both personal and external factors, which lead to differences in treatment choices and ways of administration. IBD patients with milder symptoms are more willing to accept higher-risk treatment options to avoid more severe symptoms, and men are more tolerant^[18] of the risks caused by treatment than women. In addition, the choice of delivery system in the aspects of income levels and adverse events of patients, the drug was always higher in patients with long disease duration, compared with intravenous antitumor necrosis treatment, patients prefer to choose subcutaneous injections^[19], an anti-tumor necrosis treatment methods of medicine study^[19], patients because of considering the influence of the quality of life, More inclined to choose subcutaneous injection; In the treatment of biological agents, the safety, convenience and frequency of administration will affect the choice^[20] of drug management in IBD patients. The differences in the composition of national social medical insurance and cultural background lead to the differences in the choice of treatment options for IBD patients between Asian and Western countries. In terms of drug types, IBD patients in Western countries are more likely to accept biological agents as a treatment option. As for the mode of administration, Asian patients prefer intravenous biological agents due to their greater dependence on doctors, while IBD patients in Western countries tend to choose intradermally. The differences in the composition of national social medical insurance and cultural background lead to the differences in the choice of treatment options for IBD patients between Asian and Western countries. In terms of drug types, IBD patients in Western countries are more likely to accept biological agents as a treatment option. As for the mode of administration, Asian patients prefer intravenous biological agents due to their greater dependence on doctors, while IBD patients in Western countries tend to choose intradermally^[21].

Different perceptions of the risks and benefits of treatment between healthcare workers and patients lead to different views on treatment decisions. Physicians often pay more attention to the improvement of

biological indicators and clinical symptoms of the disease, such as disease remission and disease control; While patients are more willing to focus on symptom relief and quality of life. One study showed^[22] that about 60% of UC patients with dysplasia found at the time of biopsy would reject the doctor's proposed colectomy as a treatment option, even when they were told they would have a 20% risk of bowel cancer. A cross-sectional study^[23] showed that physicians, nurses, and patients had different preferences regarding ileostomy for temporary loss of function. Physicians preferred surgery when the risk of anastomotic leakage was low, while nurses and patients considered surgery only if the risk of anastomotic leakage was higher than 25% to avoid permanent ileostomy. Dominated by the doctor's treatment decision-making model ignores the preference, the treatment of patients with obvious differences, in fact, doctors and patients with IBD treatment preferences, and personalized nursing in patients with IBD is also very important, therefore, it is necessary to carry out the SDM in patients with IBD, thus making the personalized health care plan.

4. The role of nurses in shared decision-making in IBD patients

4.1. Health information providers

Providing health education among IBD patients has been shown to increase disease knowledge and patient satisfaction with educational information and healthcare, ultimately leading to higher treatment adherence and reduced healthcare costs^[24]. Nurses are health for IBD patients to the main characters, a preference on patients with preoperative UC information qualitative study^[25], surgery on patients quality of life (such as diet, exercise and recovery of daily life for a long time, etc.) is the long-term effects of patients want to obtain information. Patients indicated that they preferred to get relevant information from nurses rather than surgeons, and patients rated ostomy or IBD specialist nurses as the first choice for providing practical information. Nurses were the best candidates to provide relevant information on nursing management, such as the similarities and differences and advantages of subcutaneous injection and intravenous injection, guidance and education of subcutaneous injection, and stoma nursing management. A survey^[26] assessing clinical practice in IBD care across Europe showed that the majority of nurses were able to independently assess patients' conditions and make recommendations for disease management. Providing patients with information about treatment and advice; Discuss the medical management of IBD with the patient; Educate the patient on the management of IBD surgery and provide information about test results.

4.2. A facilitator of medical decision making

IBD is an extremely complex chronic disease, which requires a multidisciplinary team for disease management and care. Nurses as a member of the multidisciplinary team play an important role in the SDM of IBD patients. Nurses are important personnel who provide professional nursing practice for patients and play a crucial role in clinical decision-making. A prospective study^[27] on the impact of nurse-led telemedicine services on health care costs showed that nurses provided treatment decision-making and guidance for patients through telephone consultation reduced unnecessary hospitalization and medical costs. Taylor^[28]'s study showed that nurses improved patients' choice of biologics and improved the quality of patient care. Chinese scholar Liu Yuan^[29] built a shared decision aid to assist GU patients and doctors to make decision-making tools together.

4.3. A bridge for doctor-patient communication

SDM is a patient-centered treatment decision-making model, and communication and collaboration are considered to be the core of SDM^[30]. Nurses are important personnel in providing care for IBD patients. Nurses are good at listening to the needs and suggestions of patients and family members, building a relationship of trust with patients, and encouraging patients and family members to express their opinions and preferences. A study^[32] of IBD patients after discharge showed that 98% of patients believed that telephone consultation with IBD nurses optimized communication with doctors and enabled faster appointment management. Nurses can coordinate the communication and cooperation among various professionals, which can not only convey the needs and opinions of patients to doctors, but also optimize the information provided by doctors to patients, which is conducive to the understanding of patients, promoting the communication between doctors and patients, and facilitating the application of SDM^[31].

5. Decision AIDS in IBD

Decision aids (DA) are tools to help patients make decisions. DA is a common intervention to promote SDM, and the successful use of DA is an important prerequisite for the implementation of SDM. Patients' preferences are unique, but due to the complex nature of clinical work, medical staff lack time to discuss the risks and benefits of treatment options and weigh the pros and cons of treatment options around patients in detail. Therefore, there is a need for simple and effective tools to trigger patients' treatment preferences and promote the interaction between patients and medical staff^[26,27]. Decision AIDS provide patients with detailed information about treatment options and their corresponding outcomes, help patients clarify their own values, and guide patients to choose the treatment plan that is most suitable for them. In order to improve the quality of patient decision AIDS, the International Collaboration on Patient Decision AIDS Standards has developed a series of criteria (IPDAS) to evaluate and guide the development^[33] of decision AIDS. At present, the common forms of decision AIDS for IBD patients are decision AIDS manuals, Web-based decision AIDS (interactive websites, mobile applications, videos, etc.)^[34].

5.1. Decision aid Manual

A decision aid manual is an instructional document, typically provided to patients in paper form, that is designed to provide support and assistance to decision makers so that they can make more informed, rational, and effective decisions. These manuals typically contain background information about the disease, options for various treatment options, and an assessment of the benefits, harms, and risks of different options.

Help you decide about surgery, a decision aid about IPAA and ileostomy developed by Jessica^[35] and her team for patients with UC, was initially distributed in paper form but was also developed in electronic versions in subsequent studies to address low response rates. The DA is based on the decision aid prototype developed by Luc Dubois^[36], with animated illustrations and photos added for easy use by patients. In addition to disease and surgery-related information, the decision aid manual compares the complications and risks of the two surgeries, guides the patient's surgical preference through a series of questions, and helps the patient and the doctor jointly decide on the surgical method. In addition, it provides resources to find disease-related content. In 2020, Chinese scholar Liu Yuan^[29] established a shared decision-making knowledge base through expert consultation. By assessing patients' needs for shared decision-making knowledge, nurses used the shared decision-making knowledge base to carry out daily health education for patients according to patients' needs, and promote patients and doctors to discuss relevant treatment options and make joint decisions.

The advantage of decision AIDS manual lies in providing comprehensive evidence-based information to help decision makers better understand IBD-related issues and choices. However, with the in-depth research of the pathogenesis and treatment of IBD, the clinical information related to IBD is constantly updated, while the decision AIDS manual generally exists in the form of printed matter or documents. As a result, the information updates lag and change is difficult.

5.2. Web-based decision AIDS

Web-based decision AIDS mainly include two forms: mobile applications and interactive websites. Web-based decision AIDS are widely used to help cancer patients make decisions^[37], improve the mental health^[38] of non-professional caregivers of dementia patients, etc. Web-based decision AIDS are also the most common form in IBD patients.

IBDecide^[39] is a mobile application developed by Daraiseh's team in collaboration with care providers. It is specifically provided to adolescents and young adults to use the DA themselves. IBDecide facilitates SDM and medication management for patients with IBD, fostering critical skills for the transition to adult care. IBDecide not only provides patients with treatment information, but also invites patients to think about their treatment through the interactive chatbot to ask questions, so as to understand patients' treatment preferences more comprehensively and generate a series of treatment options that are consistent with patients' responses^[39]. In addition, the APP provides patients with appointment guidelines and treatment tracking, including medication reminders to help patients with self-management^[39].

Daraiseh^[39,40] verified that IBDecide showed superiority in SDM and symptom management. Matual^[40] verified the high usability and acceptability of IBDecide in UC patients through an RCT, and patients indicated that IBDecide was rich in content and easy to use.

myAID^[41] is a Web-based multimedia DA. Some contents of myAID are presented in the form of videos, which helps patients understand the relevant information about the disease and treatment options (drug therapy, surgical treatment and alternative therapy, etc.). In addition, myAID also has an interactive part, which can elicit patients' treatment preferences and goals by asking patients about their current symptoms and treatment distress. Through a qualitative study, Kim^[42] concluded through interviews with UC patients and physicians that myAID is a feasible and acceptable tool that facilitates early doctor-patient discussion of treatment options and facilitates SDM. In addition, Kim^[41] also designed a CRCT protocol for the impact of myAID on the quality of life of UC patients, but there is a lack of data to support this hypothesis.

IBD&me^[43] (www.ibdandme.org) is an interactive, free website created by academics at Cedars-Sinai Medical Center specifically for patients considering biologics as a treatment option for IBD. It includes an education component and a series of interactive exercises, rating task patients can understand biological agents therapy on the website of relevant knowledge, and through the complete decision tree by filling in IBD "decision tree" series of problems, and finally acquire personalized preferences report, as a patient and medical staff to discuss decided to one of the types of biological agents reference. In order to detect IBD&me role of SDM, Almario^[44] devised a biological agent instruction as a control group of RCT standardization, results showed that the patients of the two forms of data showed high satisfaction, but IBD&me and biological preparation instructions there is no significant difference on promoting the SDM. The effect of IBD&me on SDM needs to be further verified.

The advantage of web-based decision AIDS lies in providing more personalized decision support to patients in real time, which is more flexible and convenient than manual, especially interactive decision AIDS. It not only provides patients with treatment, drug delivery way, operation cure scheme selection information, according to the patients to provide information for patients can also generate a personalized report, promote the patient communication and discussion with their doctor, for patients with the management of the disease itself.

6. Outcomes of the application of SDM in patients with IBD

6.1. The application of SDM in the treatment effect

6.1.1. Improve compliance

The main purpose of IBD treatment is to induce and maintain clinical remission and mucosal healing, prevent complications, and improve quality of life^[45]. Non-compliance is the main obstacle^[46] to induce and maintain remission. SDM can improve the treatment compliance of patients. A prospective study on the factors of medication nonadherence in outpatients with IBD showed that patient and physician decision inconsistency affected patient adherence to medication, and some patients intentionally did not follow doctor's advice, which led to a decrease in patient adherence^[47]. Keres^[48] study also showed that consistency in doctor-patient decision making is an important factor in improving treatment adherence. SDM supports patient and health care providers to achieve consistency in decision making based on knowledge sharing. Some scholars^[49] in the United States have conducted a cross-sectional survey of patients with IBD and immune diseases who were treated with biological agents, and pointed out that SDM can improve the medication adherence and treatment satisfaction of IBD patients, and reduce the health care cost of IBD patients who participate in SDM.

6.1.2. Improve the enthusiasm of treatment

IBD belongs to the category of chronic diseases, which brings huge psychological and economic burden to patients. Active participation in treatment decision-making has a good effect on disease control. In a cross-sectional survey of more than 1000 people in the Netherlands^[50], 87% of patients emphasized the importance of SDM for treatment. In addition, patients in this study who used SDM were able to express their treatment preferences more effectively, and SDM improved patient adherence and motivation during treatment. Previous studies^[51] have shown that the combination of infliximab and azathioprine can significantly improve and alleviate the disease in CD patients. A cluster RCT study was conducted in 14 gastroenterology clinics in the United^[52] States. The results showed that CD patients who received SDM in the early stage of the disease would choose the treatment strategy more carefully, be more active in the treatment, and choose a higher proportion of combination drugs. Using semi-structured interviews between physicians and UC patients, Kennedy^[53] concluded that SDM improved patient engagement despite differences in attitudes toward the decision aid manual, as did Veilleux^[54]'s study. Yannia^[55] conducted a retrospective cohort study to evaluate the effect of combining

SDM with a multidisciplinary clinic on rash control in IBD patients, and the results showed significant improvement in rash and good control of IBD activity. In addition, Australian scholar Jackson^[56] et al. conducted a prospective study on outpatients with IBD, and the results showed that decision support tools promoted SDM and improved the quality of care.

6.2. Application of SDM in treatment evaluation

6.2.1. Reducing decision-making conflicts

The complexity of IBD care and the heterogeneity of disease types may lead to conflicts^[57] between doctors and patients in decision-making. In a^[58] study examining the impact of a decision aid developed by a multidisciplinary team on decision quality, SDM reduced decision-making conflict and improved disease perception in pregnant women with IBD. This is consistent with the findings in Zisman-Ilan^[52]'s study, in which patients who used SDM made higher-quality decisions. But with a SDM on anti-tumor necrosis factor treatment decisions on the results obtained from the application of RCT^[59] in the family, in this study by SDM a series of family intervention with regular care of the family there were no significant differences in conflict and decision quality. This may be due to the fact that only the views of doctors and parents were considered, and the opinions and needs of children themselves were not fully considered. Moreover, the small sample size of 22 families affected the experimental results. In addition, some scholars^[60] on the use of biological agents of IBD and idiopathic arthritis in children with parents has carried on the questionnaire survey, the results show that SDM did not improve the decision conflicts, but reduces the decision regret degree, and the doctor in the process of decision-making behavior related to the degree of decision conflicts and regret.

6.2.2. SDM can improve satisfaction and promote self-management

In a Chicago study^[61] of attitudes toward SDM in IBD patients, about 66% of the study subjects indicated that SDM could improve satisfaction with decisions. Chinese scholar Liu Yuan^[29] confirmed that SDM could effectively improve the satisfaction of patients participating in medical decision-making through the study of CD patients, and the research results were consistent with the research results of Lofland^[49]. Veilleux^[54] conducted a Web-based survey of Australian patients with IBD and found that SDM reduced anxiety and improved care-related satisfaction. Japanese scholars^[62] conducted a web-based survey on UC patients to study the effect of information exchange between doctors and patients on the satisfaction of treatment decisions. The results showed that adequate information exchange between doctors and patients can improve patients' satisfaction with treatment decisions and increase patients' trust in doctors. Some scholars^[63] have validated Web-based decision AIDS (HAT), and the results show that SDM can improve patient satisfaction and clinical outcomes, which is conducive to the self-management of IBD patients. A prospective study assessing transition in adolescents with IBD, using shared goal setting and electronic health record (EHR) tracking through SDM, showed that children with IBD were highly satisfied with transition preparation services and that SDM facilitated self-management^[64].

7. Summary and Prospect

In the context of standardized treatment, personalized medical care needs have attracted more and more attention. Scholars have gradually realized that patients' health needs and treatment responses may be significantly different, and standardized treatment regimens alone cannot fully meet the needs of all patients. As an effective medical decision-making model, SDM has been proved to have advantages in treatment effect and treatment decision-making. Making nursing goals together with patients is beneficial to disease management and improve patients' compliance and enthusiasm for treatment^[65]. Therefore, SDM should be widely promoted and applied in IBD patients. The shortage of medical resources may lead to a lack of opportunities for personalized discussion between medical staff and patients, which may hinder the application of SDM in IBD patients in China. Studies have shown^[56] that DA can promote SDM and improve the quality of care. DA is helpful for medical staff and patients to efficiently discuss treatment plans in a limited time. More and more scholars abroad are committed to the research of DA, but there is little research content on the development of DA in China. At present, only scholar Liu Yuan^[29] has established a knowledge base on SDM in CD patients. Therefore, further research should focus on the development and promotion of DA, and strengthen the training of Chinese medical staff on SDM so as to promote the application of SDM in China.

References

- [1] Ng S C, Shi H Y, Hamidi N, et al. *Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies*[J]. *The Lancet*, 2017, 390(10114): 2769-2778.
- [2] Bao Y L, WANG Z, Tang H R, et al. *Burden of inflammatory bowel disease and its changing trend in China from 1990 to 2019*[J]. *General Practice in China*: 1-6.
- [3] Chen Xiaofen, Chen Yuhan, Ma Juan. *Research progress of new treatment methods for inflammatory bowel disease* [J]. *Chinese General Medicine*, 2023, 26(27): 3349-3354.
- [4] Oshima Lee E, Emanuel E J. *Shared decision making to improve care and reduce costs*[J]. *The New England Journal of Medicine*, 2013, 368(1): 6-8.
- [5] Charles C, Gafni A, Whelan T. *Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango)*[J]. *Social Science & Medicine*, 1997, 44(5): 681-692.
- [6] Hoffmann T, Bakhit M, Michaleff Z. *Shared decision making and physical therapy: What, when, how, and why?* [J]. *Brazilian Journal of Physical Therapy*, 2022, 26(1): 100382.
- [7] Wilson S R, Strub P, Buist A S, et al. *Shared Treatment Decision Making Improves Adherence and Outcomes in Poorly Controlled Asthma*[J]. *American Journal of Respiratory and Critical Care Medicine*, 2010, 181(6): 566-577.
- [8] Granados-Santiago M, Valenza M C, Lopez-Lopez L, et al. *Shared decision-making and patient engagement program during acute exacerbation of COPD hospitalization: A randomized control trial*[J]. *Patient Education and Counseling*, 2020, 103(4): 702-708.
- [9] Shinkunas L A, Klipowicz C J, Carlisle E M. *Shared decision making in surgery: a scoping review of patient and surgeon preferences*[J]. *BMC medical informatics and decision making*, 2020, 20(1): 190.
- [10] Hamann J, Holzhter F, Blakaj S, et al. *Implementing shared decision-making on acute psychiatric wards: a cluster-randomized trial with inpatients suffering from schizophrenia (SDM-PLUS)*[J]. *Epidemiology and Psychiatric Sciences*, 2020, 29: e137.
- [11] George M, Pantalon M V, Sommers M L S, et al. *Shared decision-making in the BREATHE asthma intervention trial: A research protocol*[J]. *Journal of Advanced Nursing*, 2019, 75(4): 876-887.
- [12] Probst M A, Lin M P, Sze J J, et al. *Shared Decision Making for Syncope in the Emergency Department: A Randomized Controlled Feasibility Trial*[J]. *Academic Emergency Medicine: Official Journal of the Society for Academic Emergency Medicine*, 2020, 27(9): 853-865.
- [13] Berger-Hoger B, Liethmann K, Muhlhauser I, et al. *Nurse-led coaching of shared decision-making for women with ductal carcinoma in situ in breast care centers: A cluster randomized controlled trial*[J]. *International Journal of Nursing Studies*, 2019, 93: 141-152.
- [14] Ma L, QIN L W, Miao Q Q, et al. *Effect of shared decision-making nursing on atrial fibrillation patients with radiofrequency ablation* [J]. *Qilu Nursing Journal*, 2023, 29(8): 94-97.
- [15] Xia Chunjuan, Wang Lingyun, Zhao Qiana, et al. *Application of situational cognitive intervention based on nurse-patient shared decision-making model in vaginal delivery of primiparas* [J]. *Nursing Research*, 2023, 37(6): 1099-1102.
- [16] Yang L, Song X, Chen Y, et al. *Treatment Decision-making in Chinese Inflammatory Bowel Disease Patients*[J]. *Inflammatory Bowel Diseases*, 2022, 28(Supplement_2): S76-S84.
- [17] Song K, Wu D. *Shared decision-making in the management of patients with inflammatory bowel disease*[J]. *World Journal of Gastroenterology*, 2022, 28(26): 3092-3100.
- [18] Johnson F R, Ozdemir S, Mansfield C, et al. *Crohn's disease patients' risk-benefit preferences: serious adverse event risks versus treatment efficacy*[J]. *Gastroenterology*, 2007, 133(3): 769-779.
- [19] Cha J M, Park D I, Park S H, et al. *Physicians Should Provide Shared Decision-Making for Anti-TNF Therapy to Inflammatory Bowel Disease Patients*[J]. *Journal of Korean Medical Science*, 2017, 32(1): 85-94.
- [20] van Deen W K, Khalil C, Bonthala N N, et al. *Inflammatory Bowel Disease Patients' Preferences for Subcutaneous versus Intravenous Therapies: A Mixed-Methods Study*[J]. *Digestive Diseases*, 2023, 41(3): 412-421.
- [21] Kim E S, Kim K O, Jang B I, et al. *Factors Contributing to the Preference of Korean Patients with Crohn's Disease When Selecting an Anti-Tumor Necrosis Factor Agent (CHOICE Study)*[J]. *Gut and Liver*, 2016, 10(3): 391-398.
- [22] Siegel C A, Schwartz L M, Woloshin S, et al. *When Should Ulcerative Colitis Patients Undergo Colectomy for Dysplasia? Mismatch Between Patient Preferences and Physician Recommendations*[J]. *Inflammatory bowel diseases*, 2010, 16(10): 1658-1662.
- [23] Mackay I, Clark D A, Nicholson J, et al. *Risk taking propensity: Nurse, surgeon and patient preferences for diverting ileostomy*[J]. *Colorectal Disease*, 2022, 24(9): 1073-1079.
- [24] Waters B M, Jensen L, Fedorak R N. *Effects of formal education for patients with inflammatory*

- bowel disease: a randomized controlled trial[J]. *Canadian Journal of Gastroenterology = Journal Canadien De Gastroenterologie*, 2005, 19(4): 235-244.
- [25] Baker D M, Lee M J, Jones G L, et al. The Informational Needs and Preferences of Patients Considering Surgery for Ulcerative Colitis: Results of a Qualitative Study[J]. *Inflammatory Bowel Diseases*, 2018, 24(1): 179-190.
- [26] O'Connor M, Gaarenstroom J, Kemp K, et al. N-ECCO survey results of nursing practice in caring for patients with Crohn's disease or ulcerative colitis in Europe[J]. *Journal of Crohn's and Colitis*, 2014, 8(10): 1300-1307.
- [27] Squires S I, Boal A J, Naismith G D. The financial impact of a nurse-led telemedicine service for inflammatory bowel disease in a large district general hospital[J]. *Frontline Gastroenterology*, 2016, 7(3): 216-221.
- [28] Taylor N S, Bettey M, Wright J, et al. The impact of an inflammatory bowel disease nurse-led biologics service[J]. *Frontline Gastroenterology*, 2016, 7(4): 283-288.
- [29] liu yuan. Crohn disease, such as the construction of common decision aid scheme and application research [D]. Huzhou teachers college, 2020 (in Chinese).
- [30] Elwyn G. Shared decision making: What is the work? [J]. *Patient Education and Counseling*, 2021, 104(7): 1591-1595.
- [31] Choe M Y, Wright R, Parian A. Follow-up Care in Inflammatory Bowel Disease: An Integrative Review[J]. *Gastroenterology Nursing*, 2021, 44(3): E48.
- [32] Castiglione F, Imperatore N, Testa A, et al. Efficacy of a "contact center-based communication" in optimizing the care of inflammatory bowel diseases[J]. *Digestive and Liver Disease*, 2016, 48(8): 869-873.
- [33] Holmes-Rovner M. International Patient Decision Aid Standards (IPDAS): beyond decision aids to usual design of patient education materials[J]. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 2007, 10(2): 103-107.
- [34] Zhu Zhanhui, Lin Zheng, Zhou Meijing, et al. Decision aid tool in inflammatory bowel disease in the application scope of review [J]. *Journal of nursing*, 2022, 29 (7) : 44-49.
- [35] Cohan J N, Ozanne E M, Sewell J L, et al. A Novel Decision Aid for Surgical Patients with Ulcerative Colitis: Results of a Pilot Study[J]. *Diseases of the Colon & Rectum*, 2016, 59(6): 520.
- [36] Dubois L A. The Development of a Decision Aid for Patients with Ulcerative Colitis Deciding Between Ileostomy or Ileal Anal-Pouch Reconstruction. The University of Western Ontario (Canada), 2012.
- [37] Tong G, Geng Q, Wang D, et al. Web-based decision aids for cancer clinical decisions: a systematic review and meta-analysis[J]. *Supportive Care in Cancer*, 2021, 29(11): 6929-6941.
- [38] Zhi S, Ma D, Song D, et al. The influence of web-based decision aids on informal caregivers of people with dementia: A systematic mixed-methods review[J]. *International Journal of Mental Health Nursing*, 2023, 32(4): 947-965.
- [39] Daraiseh N M, Black A, Minar P, et al. iBDecide: A web-based tool to promote engagement in shared decision-making among adolescents with ulcerative colitis[J]. *Patient Education and Counseling*, 2022, 105(6): 1628-1633.
- [40] Matula K A, Minar P, Daraiseh N M, et al. Pilot trial of iBDecide: Evaluating an online tool to facilitate shared decision making for adolescents and young adults with ulcerative colitis[J]. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy*, 2022, 25(6): 3105-3113.
- [41] Kim A H, Girgis A, Karimi N, et al. A Web-Based Decision Aid (myAID) to Enhance Quality of Life, Empowerment, Decision Making, and Disease Control for Patients With Ulcerative Colitis: Protocol for a Cluster Randomized Controlled Trial[J]. *JMIR Research Protocols*, 2020, 9(7): e15994.
- [42] Kim A H, Girgis A, Cruz P D, et al. Development and Feasibility of a Web-Based Decision Aid for Patients With Ulcerative Colitis: Qualitative Pilot Study[J]. *Journal of Medical Internet Research*, 2021, 23(2): e15946.
- [43] Chen M S, Sidorkiewicz S, Conovitz S, et al. P010 Qualitative Evaluation Of Patient Perspectives Regarding Ibd&Me (Ibdandme.Org), A Novel Online Biologic Decision Aid For Patients With Inflammatory Bowel Disease[J]. *Gastroenterology*, 2019, 156(3, Supplement): S9-S10.
- [44] Almario C V, van Deen W K, Chen M, et al. Interactive Inflammatory Bowel Disease Biologics Decision Aid Does Not Improve Patient Outcomes Over Static Education: Results From a Randomized Trial[J]. *American Journal of Gastroenterology*, 2022, 117(9): 1508-1518.
- [45] Wright E K, Ding N S, Niewiadomski O. Management of inflammatory bowel disease[J]. *The Medical Journal of Australia*, 2018, 209(7): 318-323.
- [46] Jackson B, De Cruz P. Algorithms to facilitate shared decision-making for the management of mild-to-moderate ulcerative colitis[J]. *Expert Review of Gastroenterology & Hepatology*, 2018, 12(11):

1079-1100.

- [47] Sewitch M J, Abrahamowicz M, Barkun A, et al. Patient Nonadherence To Medication in Inflammatory Bowel Disease[J]. *Official journal of the American College of Gastroenterology | ACG*, 2003, 98(7): 1535.
- [48] Kerse N, Buetow S, Mainous A G, et al. Physician-Patient Relationship and Medication Compliance: A Primary Care Investigation[J]. *Annals of Family Medicine*, 2004, 2(5): 455-461.
- [49] Lofland J H, Johnson P T, Ingham M P, et al. Shared decision-making for biologic treatment of autoimmune disease: influence on adherence, persistence, satisfaction, and health care costs[J]. *Patient Preference and Adherence*, 2017, 11: 947-958.
- [50] Baars J E, Markus T, Kuipers E J, et al. Patients' Preferences regarding Shared Decision-Making in the Treatment of Inflammatory Bowel Disease: Results from a Patient-Empowerment Study[J]. *Gastroenterologia*, 2010, 81(2): 113-119.
- [51] Colombel J F, Sandborn W J, Reinisch W, et al. Infliximab, Azathioprine, or Combination Therapy for Crohn's Disease[J]. *New England Journal of Medicine*, 2010, 362(15): 1383-1395.
- [52] Zisman-Ilani Y, Thompson K D, Siegel L S, et al. Crohn's disease shared decision making intervention leads to more patients choosing combination therapy: a cluster randomised controlled trial[J]. *Alimentary Pharmacology & Therapeutics*, 2023, 57(2): 205-214.
- [53] Kennedy A P, Rogers A E. Improving patient involvement in chronic disease management: the views of patients, GPs and specialists on a guidebook for ulcerative colitis[J]. *Patient Education and Counseling*, 2002, 47(3): 257-263.
- [54] Veilleux S, Noiseux I, Lachapelle N, et al. Patients' perception of their involvement in shared treatment decision making: Key factors in the treatment of inflammatory bowel disease[J]. *Patient Education and Counseling*, 2018, 101(2): 331-339.
- [55] Yanai H, Amir Barak H, Ollech J E, et al. Clinical approach to skin eruptions induced by anti-TNF agents among patients with inflammatory bowel diseases: insights from a multidisciplinary IBD-DERMA clinic[J]. *Therapeutic Advances in Gastroenterology*, 2021, 14: 17562848211053112.
- [56] Jackson B, Begun J, Gray K, et al. Clinical decision support improves quality of care in patients with ulcerative colitis[J]. *Alimentary Pharmacology & Therapeutics*, 2019, 49(8): 1040-1051.
- [57] Rubin D T, Cleveland N K. Using a Treat-to-Target Management Strategy to Improve the Doctor-Patient Relationship in Inflammatory Bowel Disease[J]. *Official journal of the American College of Gastroenterology | ACG*, 2015, 110(9): 1252.
- [58] Wang G, Karimi N, Willmann L, et al. A Novel Decision Aid Improves Quality of Reproductive Decision-Making and Pregnancy Knowledge for Women with Inflammatory Bowel Disease[J]. *Digestive Diseases and Sciences*, 2022, 67(9): 4303-4314.
- [59] Lipstein E A, Brinkman W B, Zhang Y, et al. Decision making about anti-TNF therapy: A pilot trial of a shared decision-making intervention[J]. *Patient Education and Counseling*, 2022, 105(5): 1075-1081.
- [60] Lipstein E A, Lovell D J, Denson L A, et al. High Levels of Decisional Conflict and Decision Regret When Making Decisions About Biologics[J]. *Journal of Pediatric Gastroenterology and Nutrition*, 2016, 63(6): e176-e181.
- [61] Siegel C A, Lofland J H, Naim A, et al. Novel Statistical Approach to Determine Inflammatory Bowel Disease: Patients' Perspectives on Shared Decision Making[J]. *The Patient - Patient-Centered Outcomes Research*, 2016, 9(1): 79-89.
- [62] Matsuoka K, Ishikawa H, Nakayama T, et al. Physician-patient communication affects patient satisfaction in treatment decision-making: a structural equation modelling analysis of a web-based survey in patients with ulcerative colitis[J]. *Journal of Gastroenterology*, 2021, 56(9): 843-855.
- [63] Cross R K, Cheevers N, Finkelstein J. Home Telemanagement for Patients with Ulcerative Colitis (UC HAT)[J]. *Digestive Diseases and Sciences*, 2009, 54(11): 2463-2472.
- [64] Huang J S, Yueh R, Wood K, et al. Harnessing the Electronic Health Record to Distribute Transition Services to Adolescents With Inflammatory Bowel Disease[J]. *Journal of Pediatric Gastroenterology and Nutrition*, 2020, 70(2): 200.
- [65] Dillon D L, Crimaldi J E. Pathway-Driven Management of Inflammatory Bowel Disease[J]. *The Journal for Nurse Practitioners*, 2020, 16(7): 493-497.