Self-management support given by specialist nurses in patients with Inflammatory Bowel disease. A thematic analysis

Date:	10-08-2012
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Course:	master thesis
Version:	Final version

Peer review journal:	Gastroenterology Nursing
Reference style:	American Psychological Association (APA)
Number of words:	Article: 3491
	English abstract: 299
	Dutch abstract: 296

Introduction

Inflammatory Bowel disease (IBD) is a chronic disease also known as Ulcerative Colitis (UC) or Crohns' disease (CD). Characterized by periods of exacerbations and remission, the severity of symptoms like abdominal pain, bloody diarrhea, fecal urgency and weight loss, fluctuates unpredictable overtime (Albersnagel, 2007; Kennedy, 2004). These symptoms can disable patients e.g. on education, work and social life due to problems such as fatigue, loss of control, negative body image and feelings of fear and isolation (Casati, 2000). Treatment of IBD focuses on prolonging the periods of remission (Albersnagel 2007; Robinson 2008; Lakatos, 2009). Patients require lifelong treatment consisting of medical management, lifestyle changes and, sometimes, surgical intervention (Albersnagel, 2007; Lakatos, 2009). Literature indicates treatment of IBD to be a complex process due to adverse effects, complications (Robinson, 2008; Turnbough, 2007) and non-adherence among medication and lifestyle changes (Albersnagel, 2007; Robinson, 2008; Turnbough, 2007). Swift treatment of exacerbations is important. Therefore, guided self-management support seems a suitable strategy in IBD treatment (Kennedy, 2004; Robinson, 2001).

Self-management

According to Lorig (2003) patients are responsible for their day-to-day care in managing their chronic disease, which can be described as self-management. Barlow (2002) defined self-management as '*the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic disease'.* To enable patients to manage their disease, self-monitoring is required (Barlow, 2002). Barlow (2002) states: *'the ability to monitor one's condition and to affect the cognitive, behavioral and emotional responses is necessary to maintain a satisfactory quality of life'.* To accomplish effective self-management, patients need a certain level of self-efficacy and positive outcomes expectations for behavior change (Bandura, 2004).

Self-management support

The Institute Quality for Health Care CBO (2009) has developed a Generic Self-Management Model, which corresponds to Bodenheimers' (2002) description of patient education that self-management education consists of teaching patients problem-solving skills. These skills enable patients to identify problems from their own point of view and solve them using action plans applicable to the medical, social and emotional aspects of their illness.

Within literature, little research has been conducted on nursing interventions and self-management support strategies for IBD patients although self-management interventions

seem to have a positive effect on the treatment of symptoms (Robinson, 2001), quality of life, fear (Kennedy, 2004) and patient satisfaction (Kennedy, 2004; Robinson, 2001). A self-support group of IBD-patients arranging their own meetings seemed to contribute to a better quality of life and self-management in IBD (Krause, 2003). Research on patient education shows temporary increase of knowledge about IBD (Quan, 2003; Waters, 2005). A comprehensive lifestyle modification program of stress-management training, relaxation techniques and psycho-educational elements, showed short-term benefits in self-management of patients with UC (Langhorst, 2007). Nurse counseling by telephone for medication adherence showed no significant effect on adherence and quality of life on patients with UC (Cook, 2010; Moss, 2009). Patient-centered care and open access consultation are strategies considered to support guided self-management (Robinson, 2001; Kennedy, 2004).

Problem statement

In the Netherlands IBD patients receive nurse counseling at outpatient clinics. During these consults, patients are educated by specialized IBD nurses in order to support their self-management. Scientific evidence being scarce it remains unknown how nurses can support IBD patients' self-management. It is also unknown which strategies IBD nurses use to support self-management. It is presumed that IBD nurses have insight in effective nursing interventions or strategies in order to support self-management. This research aims to obtain information about the tacit and self evident practical knowledge of nurses to support self-management of IBD patients.

Aim of the research

The objective of this research is to explore how IBD nurses, in the Netherlands, support self-management in patients with IBD. The identification of nursing interventions and strategies, used during nursing consultation and counseling, could contribute to the development of self-management programs in patients with IBD.

Research questions

The main research question is: 'How do IBD nurses support self-management of patients with IBD?' This question is split in two sub questions:

- Which perceptions do IBD nurses have on self-management?
- Which interventions and strategies do IBD nurses use in order to support patients' self-management?

For the purpose of this research a nursing intervention is defined as described by McCloskey and Bulechek: *'Any treatment, based upon clinical judgment and knowledge, that a nurse performs to enhance patient/client outcomes'* (Steelman, 1994). Strategy is defined as '*a plan that is intended to achieve a particular purpose'* (Oxford advanced learner's dictionary, 8th edition). Differing from quantitative research i.e. statistically testing effectiveness of interventions ('t Hart, 2005), this research derives effectiveness from expert opinion, i.e. based on the perceptions of IBD nurses.

Methods

Design

A generic qualitative study design was selected to explore IBD nurses' experiences and perspectives on self-management support (King & Horrocks, 2010). Rather than developing a new theory of self-management, this study explored the meaning of the concept of self-management, strategies and interventions used in self-management support of patients with IBD through thematic analysis, combining both inductive and deductive approach (King & Horrocks, 2010).

Study population

The study population consisted of IBD nurses working in the Netherlands. A purposive sample of 14 respondents was taken, corresponding to the template analysis (King & Horrocks, 2010). Respondents were included when meeting both inclusion criteria: having an IBD nursing, nurse practitioner or specialist nurse IBD qualification and having consulting hours at a hospital outpatient clinic. The exclusion criterion consisted of a work experience as IBD nurse for less than two years. Respondents were sought from January till June 2012 by searching hospital websites for IBD nursing consultation hours. If available, IBD nurses were requested by e-mail or telephone to participate.

Data collection

Respondents were included to the study after they confirmed informed consent. Data was collected through semi-structured interviews (King & Horrocks, 2010), to ensure all themes were discussed while allowing respondents to speak openly about their experiences. The interview guide contained the following topics: self-management, nursing interventions, strategies used within self-management support and perceived results. (table 1). Interview duration varied from 35 till 68 minutes. The interviews took place at the hospitals where the respondents worked. The interviews were audio-taped. The researcher made field notes and reflection memos after the interviews were conducted.

Data analysis

The interviews were transcribed literally and analyzed through coding and matrix-and-template analysis (King & Horrocks, 2010). Firstly, three interviews were analyzed by open coding. Themes derived from the data included research concepts like self-management, interventions and strategies. Secondly, interview four and five were open coded. Corresponding codes were clustered into categories. Based on these categories a matrix analysis was developed which included the respondents' quotes, hereby obtaining a broad picture of key issues (King & Horrocks, 2010). The remaining interviews were coded by existing categories; new themes within these data were noted as new codes and were placed into the matrix analysis. Thirdly, key themes were derived by deductive coding and a template analysis was developed. (figure 1) New themes were derived while checking the template analysis during the last two interviews.

Validity and reliability

The quality of this research was ensured through peer review and memos (Holloway & Wheeler, 2006)

Validity was ensured by using interview techniques like summarizing, repeating or paraphrasing the interviewees' words. Four respondents were approached to check the results of the thematic analysis, none responded in time. Transparency and objectivity within the research process were ensured by peer review. Transcripts, codes, memos and methodological decisions were discussed with the supervisor. The memos consisted of field notes, reflection notes, notes on methodological decisions and data analysis.

Results

There were 21 respondents approached to participate in this study. There was a non-response of 10 due to: lack of time, participation in other research and unknown due to non-response to email. Eleven respondents were interviewed. Their characteristics are mentioned in table 2.

Concerning self-management, three main themes were derived from the data: self-monitoring, adherence to medication, attending outpatient appointments for medical examination and management of IBD in daily life. Main interventions used by IBD nurses during consulting hours are: patient education, self-monitoring support and references to other disciplines. Data analysis showed open access consultation, patient-centered care and partnership to be main strategies used by IBD nurses within self-management support.

Self-management

To manage IBD, patients need to have knowledge about the disease and its treatment; this knowledge is obtained during consultation hours. Additionally, effective self-management behavior is affected by disease acceptance, experience, self–reliance and adaptation to structured lifestyle. Disease acceptance is essential for managing IBD because patients need to self-monitor their situation and decide to contact the IBD nurse for additional treatment themselves. They also need to adhere to their medication regimen and to attend regular outpatient appointments for medical examination during periods of exacerbation and remission.

'at all times there will be people who will never accept it, they keep disregarding it and for those people it is going to be difficult to achieve self-management.' (respondent 1)

Self-monitoring

To manage IBD patients need to be able to distinguish increasingly severe symptoms or exacerbation from common illness accounting factors like periods of prolonged stress or overreaction to food. By observing the frequency of fecal urgency, bloody diarrhea, bloating and abdominal pain, patients learn to decide if additional treatment is needed. IBD patients have to recognize adverse effects of medication. Years of experience in living with IBD and self-reliance are important factors in self-monitoring. Patients suffering from IBD longer than two years develop insight into their physical functioning e.g. they experienced the effect of stress or food on IBD and know under which conditions the severity of symptoms increase. Through experience, patients learn to cope with the symptoms and develop confident decision-making.

'patients visit the consultations hours 4 times a year 30 minutes, but the rest of the time patients need to be self-reliant in deciding 'when do I contact the nurse' or 'what do I have to do at this moment' (respondent 2)

An important part of self-management support consists of training patients' self-monitoring through education and counseling. During consultation, patients are coached in self-monitoring by asking to interpret symptoms themselves. By discussing these interpretations with the IBD nurse, patients learn to distinguish exacerbations from illness. A diary, which is sometimes given, may offer additional insight.

Adherence to medication and lifestyle changes

Various medications are being used to treat IBD, e.g. 5-ASA-preparates, corticosteroids, immunosuppressives and biologicals. Medication regimen depends on the severity of symptoms. Prednisolone treatment for exacerbations takes place under supervision of IBD nurses, checking on (adverse) effects and supporting gradual lowering of its dosage. Self-management regarding medication includes more frequent use of enemas and suppositories to treat proctitis or UC, or by increasing dosage of 5-ASA-preparates when symptoms increase in severity. IBD nurses experience non-adherence among IBD, caused by non-acceptance of disease, adverse effects or aversion to medication. IBD nurses emphasize patients that adherence to medication is imperative in keeping IBD under control. Therefore nurses check adherence by asking questions about medication and, when necessary, try to find out the reasons behind non-adherence. The importance of adherence will be repeated, otherwise lowering dosage or changing the frequency or the way medication is administered (e.g. tabs, granulates, enema) will be discussed. IBD nurses incidentally emphasize the importance of adherence to prevent operations or cancer. Motivational interviewing is used to support adherence and lifestyle changes e.g. patients are asked to consider how they could benefit from medication adherence or giving up smoking thus motivating them to adapt their lifestyle.

A varied diet and giving up smoking and alcohol are the main lifestyle changes which are being advised. The IBD nurse either tries to make giving up smoking negotiable or tries to arrange support when patients desire to give up smoking.

Attending outpatient appointments

IBD patients with immunosuppressive medication need to attend hospital for examinations every 3 months. Compliance to frequent blood tests protects patients from severe adverse effects like liver dysfunction, pancreatitis or complications during the use of immunosuppressives. Non-attendance tends to occur when patients get used to their medication or when they experience a prolonged period of remission upon which IBD nurses re-emphasize that patients' compliance to medical review is essential for safe use of medication. When still non-attendant, IBD nurses reprimand patients on their behavior and strongly advise to adhere to medical examination. When this fails, patients are told to see their specialist to discuss alternative medication upon which patients usually start to attend.

Management of IBD in daily life

IBD affects many aspects of daily life. Patients suffer fatigue during both exacerbation and remission. Unpredictable change in severity of symptoms makes adaptation of daily life to IBD a complex process. IBD nurses support patients that experience difficulties in adapting their activities to their condition e.g. by emphasizing the need for a structured, balanced lifestyle to prolong remission, thus helping to balance work, education and social life. Because patients cope individually with IBD, they are advised to attempt to live daily life as they prefer. IBD nurses encourage patients to undertake sport and social activities. Many problems are caused by food so patients need to gain experience as to what they can eat. Other problems which IBD patients experience are incomprehension of close relatives and colleagues, difficulties with sexuality or pregnancy and restrictions on holiday destinations when being prone to illness due to immunosuppressive medication.

Patient education

IBD nurses explain the characteristics of IBD to ensure patients can cope with IBD and will be able to recognize and treat exacerbations in time, giving information about the disease, treatment regimen, adherence and lifestyle, diet, relation between UC, CD and cancer, the sufferers association (CCUVN) and the role of IBD nurses as partner in self-management care. Pregnancy may be discussed if suitable. IBD nurses support patient education with information booklets (Ferring), leaflets, the website of CCUVN or 'MDL life' magazine. Additionally IBD nurses use drawings, photographs, torsos and PowerPoint-presentations. Instructing patients on methotrexaat and Humira® injections is done either by using demonstration materials or instructing patients to administer injections to them under supervision of an IBD nurse

Information given during the first consultation is usually overwhelming so IBD nurses instruct patients to contact them by telephone or e-mail should questions or problems arise. Additional consultation is possible to discuss the impact of IBD on daily life. Subsequent consultation is used to emphasize adherence and healthy living.

'I always tell them, while giving them the booklet, this is a good booklet, but don't read it completely, just collect the information that you need at this moment.' (respondent 3)

Reference to other disciplines

In case of exacerbation or if medical treatment needs adjustment a physician is consulted. IBD nurses may refer to a dietitian if patients keep worrying about diet or weight loss and refer to a psychologist or social worker if patients are unable to adapt their life to IBD or suffer from depression or fatigue. Many patients experience difficulties in managing IBD while at work and hesitate about informing their employer of their disease. In some cases IBD nurses have advocated for their patients by contacting employers. All nurses refer employed patients to their corporate physician. In order to support a patients´ self-management nurses also refer to the CCUVN for up-to-date information and contact with fellow patients. IBD nurses may refer to sexologists and outpatient clinics or general practitioners for health programs e.g. to 'quit smoking'.

Open access consultation

The main strategy of IBD nurses to support self-management is open access consultation. Patients may contact the IBD nurse by telephone or email for advice or to discuss their concerns during opening hours of the outpatient clinic. Open access consultation is promoted as especially useful for inexperienced patients and patients who have difficulties in self-monitoring or decision-making in self-treatment. Open access consultation supports development of these skills, which are necessary for successful treatment, decreasing disease symptoms and achieving quality of life.

Partnership

The relation between patient and IBD nurse is considered to be important for effective self-management support. IBD nurses attempt to create an environment where patients are able to speak openly about their experiences and problems in living with IBD. They aim to become a buddy of the IBD patient, and by using motivational interviewing and thinking along, letting patients determine solutions for their problems. The attitude of the nurse is considered essential and should be characterized by: respect, empathy and taking time to listen carefully. Some nurses mentioned that judgment on non-adherence could harm the

relationship with the patient. Others found it important to criticize non-adherence because of its negative effect on medical treatment.

Patient-centered care

To enable patients to manage their disease, IBD nurses attempt to meet patients' needs by focusing on current problems. Patients are asked which subjects they want to discuss during consultation hour. If none, the IBD nurse starts a conversation by informing about the patients' condition and personal situation to explore whether information or counseling is needed. Another strategy, used by IBD nurses when acquainted with a patient's situation, is to bring up relevant subjects that otherwise would not be discussed such as problems within social support, sexuality or fistula.

*People told me they went 10, 20 times to the toilet. I said that's a severe problem, how's the condition of your anus? Don't you have pain while you're sitting on the toilet? That's how I try to openly talk about it so people feel that they can ask me for advice' (*respondent 8)

IBD nurses adjust patient education to the intellectual capability and the situation of the patient e.g. adapting education to information the patient already found on the internet. Some nurses developed leaflets on subjects like medication or coping with fatigue to inform patients beyond the scope of general information booklets when needed.

Discussion

The results of this study show that self-management of IBD patients consists of self-monitoring, adherence to medication and hospital appointments, and management of IBD in daily life, which correspond to the concept of self-management as stated by Barlow (2002). And confirms the role of patient education and reference to other disciplines as main interventions of self-management support for IBD patients as found by Barlow (2010). This study showed that interventions to support lifestyle changes and adherence mainly consist of negotiation and emphasizing the importance of behavioral change. Though motivational interviewing is considered an important intervention to support adherence in chronic diseases (Butterworth, 2008), it was seldom used by IBD nurses, possibly because few IBD nurses knew about, or were experienced in motivational interviewing. There was little attention for supporting self-efficacy, although IBD nurses consider self-confidence an important factor in self-monitoring and effective self-management, which is also confirmed by Bandura (2004). Corresponding to the developed self-management programs (Kennedy, 2004; Robinson, 2001), strategies to enable patients' self-management were open access

consultation, partnership and patient-centered care. This study shows that open access consultation is mainly used for coaching self-monitoring and self-treatment. Patient-centered care usually is achieved by adjusting education and counseling to patients' needs and preferences (Kennedy, 2004), although IBD nurses emphasize the need to discuss taboo subjects like sexuality and fistula.

This study is methodologically limited by its homogeneous study population, limiting the data variation needed for matrix analysis, resulting in a relatively narrow picture of self-management support while aiming to achieve a broad picture. Saturation did not occur, because new themes were derived from the data during the last two interviews. This study only shows the perspectives of IBD nurses on self-management support. The perspectives of IBD patients on self-management, their opinion on the provided self-management support and its usefulness are still unknown. During the time this study was conducted, a congress about IBD and fatigue was held. Therefore, it is possible that fatigue was more often mentioned as main problem in managing IBD in daily life. Although it is known that IBD patients suffer from fatigue (Casati, 2000).

Conclusion

This study explored self-management support among IBD patient by IBD nurses. The results confirm that self-management consists of self-monitoring one's condition, adherence and physical, social and emotional management of IBD in daily life. With this study no additional interventions were found. Main strategies for self-management support are open access consultation, partnership and patient-centered care. Initiating discussion about taboo subject is considered to be an important strategy to support self-management of IBD among sexuality or treatment of fistula. Based on the results of this study it is recommended that IBD nurses use scientific knowledge within their self-management support, e.g. to implement motivational interviewing and self-efficacy support in their practice. Further research is needed to determine the effectiveness of self-management support in IBD nursing care. Within self-management, the role of self-efficacy support needs to be identified, including its implications for nurse counseling during consulting hours. The results of this study warrant recommendation of paying attention to achievement of partnership within the treatment of IBD, to enable patients to speak openly about their experiences and problems. On the other hand, IBD nurses must go beyond demanded care and initiate discussion of taboo subjects supporting patients in managing problems within social support, sexuality of fistula.

References

Albersnagel, F., & Dijkstra, G. (2007). Inflammatory bowel disease. medical and psychological aspects. [Inflammatoire darmziekten. Medische en psychologische aspecten.] *Psychologie & Gezondheid, 35*(2), 85-96.

Bandura, A. Health promotion by social cognitive means. (2004) *Health Education & Behavior, vol.31(2): 143-164*

Barlow, C., Wright, C., Sheasby, J., Turner, A., Hainsworth,J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling vol. 48(2): 177-187*

Barlow, C., Cooke, D., Mulligan, K., Beck, E., & Newman, S. (2010). A critical review of self-management and educational interventions in inflammatory bowel disease. *Gastroenterology Nursing : The Official Journal of the Society of Gastroenterology Nurses and Associates, 33*(1)

Bodenheimer,T., Lorig, K., Holman, H., Grumbach, K. (2002) Patient self-management of chronic disease in Primary Care. *Journal of the American Medical Association vol. 288, no. 19*

Butterworth, S.W. (2008) Influencing patient to treatment guidelines. *Journal of Managed Care Pharmacy vol.14(6): 21-4*

Casati, J., Toner, B. B., De Rooy, E. C., Drossman, D. A., & Maunder, R. G. (2000). Concerns of patients with inflammatory bowel disease: A review of emerging themes. *Digestive Diseases and Sciences, 45*(1), 26-31

Centraal Begeleidingsorgaan/ Kwaliteitsinstituut voor de Gezondheidszorg CBO.(2009) Landelijk actieprogramma Zelfmanagement 'Kort & Krachtig' *Het Generiek Zelfmanagement Model.* www.zelfmanagement.com/tools/modellen retrieved 09-12-2011

Cook, P. F., Emiliozzi, S., El-Hajj, D., & McCabe, M. M. (2010) Telephone nurse counseling for medication adherence in ulcerative colitis: A preliminary study. *Patient Education and Counseling*

't Hart, H., Boeije,H., Hox, J. (2005) *Onderzoeksmethoden.* Den Haag: BOOM Onderwijs

Holloway, I. en Wheeler, S. (2006) *Qualitative research in Nursing*. Oxford: Blackwell Science Ltd

Kennedy, A. P., Nelson, E., Reeves, D., Richardson, G., Roberts, C., Robinson, A., et al. (2004). A randomised controlled trial to assess the effectiveness and cost of a patient orientated self management approach to chronic inflammatory bowel disease. *International Journal of Gastroenterology and Hepatology (No. 53)*

King, N. en Horrocks, C. (2010) *Interviews in Qualitative Research*. London: SAGE

Krause, M. (2003). The transformation of social representations of chronic disease in a self-help group. *Journal of Health Psychology, 8*(5), 599-615

Lakatos, P. L. (2009). Prevalence, predictors, and clinical consequences of medical adherence in IBD: How to improve it? *World Journal of Gastroenterology : WJG, 15*(34), 4234-4239

Langhorst, J., Mueller, T., Luedtke, R., Franken, U., Paul, A., Michalsen, A., et al. (2007). Effects of a comprehensive lifestyle modification program on quality-of-life in patients

with ulcerative colitis: A twelve-month follow-up. *Scandinavian Journal of Gastroenterology, 42*(6), 734-745

Lorig, K., Holman, H. (2003) Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26 (1): 1-7)*

McCloskey, J.C. en Bulechek, G.M. (red.) (1997), *Verpleegkundige interventies* [vertaling: Seunke, W. en Van Pinksteren, I.]. Maarssen: Elsevier / De Tijdstroom

Moss, A. C., Chaudhary, N., Tukey, M., Junior, J., Cury, D., Falchuk, K. R., et al. (2009) Impact of a patient-support program on mesalamine adherence in patients with ulcerative colitis - A prospective study. *Journal of Crohn's and Colitis 4(2): 171-5*

Oxford University Press (2010) *Oxford Advanced Learner's Dictionary of Current English 8th Edition*. Oxford University Press

Robinson, A. (2008). Review article: Improving adherence to medication in patients with inflammatory bowel disease. *Alimentary Pharmacology and Therapeutics, 27*(SUPPL. 1), 9-14

Robinson, A., Thompson, D. G., Wilkin, D., & Roberts, C. (2001). Guided self-management and patient-directed follow-up of ulcerative colitis: A randomised trial. *Lancet, 358*(9286), 976-981

Steelman, V.M., Bulechek, G.M., McCloskey, J.C. (1994) Toward a standardized language to describe perioperative nursing. *Association of periOperative Registered Nurses, 60 (5): 786-90, 793-5*

Quan, H., Present, J. W., & Sutherland, L. R. (2003). Evaluation of educational programs in inflammatory bowel disease. *Inflammatory Bowel Diseases, 9*(6), *356-362*

Turnbough, L., & Wilson, L. (2007). "Take your medicine": Nonadherence issues in patients with ulcerative colitis. *Gastroenterology Nursing : The Official Journal of the Society of Gastroenterology Nurses and Associates, 30*(3), *212-7*

Waters, B. M., Jensen, L., & Fedorak, R. N. (2005). Effects of formal education for patients with inflammatory bowel disease: A randomized controlled trial. *Canadian Journal of Gastroenterology = Journal Canadien De Gastroenterologie, 19*(4), 235-244.

Dutch summary

Titel: Verpleegkundige ondersteuning van zelfmanagement bij patiënten met Inflammatory Bowel Disease (IBD). Een thematische analyse.

Inleiding een redelijk nieuwe ontwikkeling in de behandeling van IBD is zelfmanagementondersteuning. Onbekend is welke interventies en strategieën IBD-verpleegkundigen gebruiken in het ondersteunen van IBD- patiënten tijdens het verpleegkundig spreekuur.

Doel: inzicht verkrijgen in zelfmanagementondersteuning aan IBD-patiënten tijdens het verpleegkundig spreekuur. Hoofdvraag van dit onderzoek was: Hoe ondersteunen IBD-verpleegkundigen het zelfmanagement van patiënten met IBD?

Methode: een algemeen kwalitatief onderzoek is uitgevoerd volgens een thematische analyse. Hiervoor werden IBD-verpleegkundigen, werkzaam op een polikliniek in Nederlandse ziekenhuizen, geïnterviewd. Dataverzameling bestond uit semigestructureerde interviews. Interviews werden geanalyseerd door coderen, matrix-, en template analyse.

Resultaten: elf IBD-verpleegkundigen zijn geïnterviewd. Zelfmanagement bestaat uit zelfmonitoring, therapietrouw, komen naar poliklinische controleafspraken en omgaan met IBD in het dagelijks leven. Belangrijkste interventies zijn: patiënteneducatie en doorverwijzen. Gehanteerde strategieën zijn: laagdrempelig contact, vertrouwensrelatie en patiëntgerichte zorg. Laagdrempelig contact was een voorwaarde in het coachen van zelfmonitoring. Motivational interviewing en self-efficacy ondersteuning werden incidenteel toegepast. Het belang van het bespreken van taboe onderwerpen benadrukt in het omgaan met problemen rondom seksualiteit of het behandelen van fistels.

Conclusie: zelfmanagementondersteuning is gericht op zelfmonitoring. Zelfvertrouwen is een belangrijke voorwaarde voor effectief zelfmanagement. De noodzaak tot leefstijlverandering en therapietrouw word herhaaldelijk bespreekbaar gemaakt. Incidenteel worden motivational interviewing en self-efficacy ondersteuning toegepast. Het hebben van een vertrouwensband met de patiënt is een voorwaarde in het bespreekbaar maken van taboe onderwerpen.

Aanbevelingen: nader onderzoek is nodig naar de betekenis van motivational interviewing en self-efficacy bij zelfmanagementondersteuning aan IBD-patiënten. Praktijkaanbevelingen

omvatten het aandacht hebben voor het opbouwen van een vertrouwensrelatie met IBD-patiënten voor een optimale behandeling waarin taboe onderwerpen als seksualiteit en fistels openlijk besproken worden zodat patiënten beter kunnen omgaan met hun problemen.

Trefwoorden: zelfmanagement, verpleegkundig, Inflammatory Bowel Disease, poliklinische patient

English abstract

Title: Self management support given by specialist nurses in patients with Inflammatory Bowel Disease (IBD). A thematic analysis

Background: self-management support is considered a relatively new concept in treatment of IBD. Scientific evidence on nursing interventions and strategies used to support self-management is scarce and little is known about self-management support given by IBD nurses during consultation hours.

Aim and research questions: to explore self-management support for patients with IBD and identify nursing interventions and strategies. Main research question was: How do IBD nurses support self-management of patients with IBD?

Method: A generic qualitative research was conducted using thematic analysis. IBD nurses working at outpatient clinics in the Netherlands were interviewed. Data was collected through semi-structured interviews and analyzed through coding and matrix- and template analysis.

Results: Eleven IBD nurses were interviewed. Self-management consists of self-monitoring, medication adherence, attendance of outpatient appointments and managing IBD in daily life. Main interventions were patient education and reference to other disciplines. Open access consultation, partnership and patient-centered care were important strategies in self-management support. Incidental use of motivational interviewing and self-efficacy support has been shown. Initiating discussion among taboo subject was considered to be important to increase the self-management of IBD patients.

Conclusion: self-management support mainly focused on training self-monitoring. Confidence was considered necessary to achieve effective self-management. Lifestyle change and adherence were supported through negotiation and emphasize of benefit. Motivational interviewing and self-efficacy were incidentally used. Partnership was considered key strategy to discuss taboo subjects.

Recommendations: further research is needed to determine the role of self-efficacy and motivational interviewing within self-management of IBD. For daily practice, attention to partnership within the treatment of IBD and initiating discussion about taboo subjects such as sexuality and fistula, is recommended to increase patients' self-management.

Keywords: self-management support, nursing, Inflammatory Bowel Disease, outpatient

Appendixes

interview guide and topic list during the first three interviews
About patient population: - What can you tell about population size, sex, age and duration of having IBD of the IBD patients who visit your consultation hours? - How do you maintain contact with IBD patients who receive self management support at your outpatient clinic?
How do you perform your job during consults concerning: - a patient who has recently been diagnosed with IBD? - a patient with exacerbated IBD? - a patient in remission?
What do you emphasize during consultation?
How do you support self management during consults with patients? - what is your perception on self-management support in patients with IBD? - which opportunities do you perceive for self management support? - which facilities to support self management are at your disposal?
Which strategies do you use to support self management? - who initiates the discussion? - where do you start? - how do you support an IBD patient in self management - how do you adapt your support
How do you support self management in a period of remission?
How do you support self management in a period of exacerbation?
How do you notice the influence of your support on a patients' self management?

Table 1: interview guide

TEMPLATE ANALYSIS

1. Self-management skills
   - 1.1. Self-monitoring
     - 1.1.1. Recognizing disease symptoms
     - 1.1.2. Interpreting severity of symptoms
   - 1.2. Adherence
     - 1.2.1. Medication
     - 1.2.2. Lifestyle
       - 1.2.2.1. Smoking
       - 1.2.2.2. Alcohol
       - 1.2.2.3. Structure rest-activity
       - 1.2.2.4. Food
     - 1.2.3. Attending hospital appointments
       - 1.2.3.1. Consultation hours
       - 1.2.3.2. Medical checkup
     - 1.2.4. Patients responsibility
   - 1.3. Management of IBD in daily life
     - 1.3.1. Food / diet
     - 1.3.2. Social activities
     - 1.3.3. Work / study
     - 1.3.4. Family life
     - 1.3.5. Pregnancy
     - 1.3.6. Fatigue
     - 1.3.7. Social support and relations
2. Factors influencing self-management
   - 2.1. Disease acceptance
   - 2.2. Self-reliance
     - 2.2.1. Years experiencing IBD
   - 2.3. Aversion to medication
   - 2.4. Negative experiences with adverse effects
3. Self-management support
   - 3.1. Intervention
     - 3.1.1. Patient education
       - 3.1.1.1. Adjusted
       - 3.1.1.2. Repeated
         - 3.1.1.2.1. Oral
         - 3.1.1.2.2. Leaflets
         - 3.1.1.2.3. Booklets
         - 3.1.1.2.4. Internet
     - 3.1.2. Reference to disciplines
     - 3.1.3. Reference to CCUVN
   - 3.2. Strategies
     - 3.2.1. Open access consultation
       - 3.2.1.1. Coaching self-monitoring
       - 3.2.1.2. Building relationships
     - 3.2.2. Partnership
       - 3.2.2.1. Nurse attitude
         - 3.2.2.1.1. Respect
         - 3.2.2.1.2. Empathy
         - 3.2.2.1.3. Taking time / listening carefully
         - 3.2.2.1.4. Non judgment vs. criticizing non-adherence
         - 3.2.2.1.5. Advocate
         - 3.2.2.1.6. Hopeful, positive
     - 3.2.3. Patient-centered care
       - 3.2.3.1. Meeting patients' needs
         - 3.2.3.1.1. Asking for subjects
         - 3.2.3.1.2. Exploring subjects through conversation
         - 3.2.3.1.3. Bringing up taboo subjects
       - 3.2.3.2. Adjusting
         - 3.2.3.2.1. IQ
         - 3.2.3.2.2. Knowledge
         - 3.2.3.2.3. Life style
         - 3.2.3.2.4. Preferences

Figure 1:template analysis

respondent	age	education (a)	experience (years)	setting (b)	region (c)
1	31	NP io	6	GH	w
2		IBD	2	GH	w
3	57	IBD	4	GH	w
4	42	NP io	9	GH	w
5	32	IBD	5	GH	w
6	33	IBD	5	GH	m
7	33	NP io	2	GH	s
8	51	IBD	8	GH	m
9	38	NP io	2.5	GH	w
10	61	NP	11	TH	m
11	50	NP	8	GH	s

(a) IBD= qualified IBD nurse, NP io= master of advanced nurse practice in training, NP= master of advanced nurse practice

(b) TH= teaching hospital, GH= general hospital

(c) w= western region of the Netherlands, m= middle region of the Netherlands, s= southern region of the Netherlands

Table 2: Characteristics of the respondents