Postprint Version	1.0
Journal website	http://www.ecco-jccjournal.org/article/S1873-9946(13)00140-2/abstract
Pubmed link	http://www.ncbi.nlm.nih.gov/pubmed/23660489
DOI	10.1016/j.crohns.2013.04.001

May you never forget what is worth remembering: The relation between recall of medical information and medication adherence in patients with inflammatory bowel disease.

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ABSTRACT

Background: Nurses play an important role in educating patients with inflammatory bowel disease (IBD) about immunosuppressive or biological therapy during prescribing consultations.

The education for immunosuppressive or biological therapy often contains complex information.

Poor medication intake behavior can be a result of poor information recall, which is often caused by complex information.

Objectives: The aim of this study is to measure information recall by IBD patients, and to investigate the relationship between recall and medication intake behavior.

Methods: Data collection took place from September 2009 until March 2012. Eight nurses at six Dutch hospitals and 68 IBD patients participated in this study. Prescribing consultations were videotaped and patients completed surveys immediately after the consultation and after three weeks. Information recall was based on the actual communication in video recordings of the consultations. Medication intake behavior was measured by self-report.

Results: Issues most frequently discussed were side effects and how patients had to administer their medication. IBD patients could reproduce half of the information. Recall of medical information was a significant predictor for self-reported medication intake behavior ($\beta = 0.37$, $p = 0.007$), indicating that higher

recall of medical information relates to improved self-reported medication intake behavior.

Conclusions: This study revealed a significant relation between IBD patients' recall and self-reported medication intake behavior. When educating IBD patients about their newly prescribed medication, providers should consider recall-promoting techniques to increase medication intake behavior.

INTRODUCTION

It is increasingly recognized that medication intake behavior is complex. Taking medication is a process in which three phases can be distinguished: the initiation (the patient takes the first dose), the implementation or execution (the patient's behavior corresponds with the prescribed regimen) and the discontinuation (the end of the regimen is marked).[1] Although appropriate medication intake behavior can reduce the chance of relapse in inflammatory bowel disease (IBD) patients, patients often do not take their medication as prescribed (phase 2). For example, Kane and colleagues[2] found that patients who failed to adhere to their maintenance medication had a 61% chance of relapse, compared with just 11% among those patients who did take their medication as prescribed. A review involving patients with IBD showed nonadherence rates varying from 7% to 72% for long-term therapies, with most studies reporting 30% to 45% nonadherence.[3] Although some associations have been found, demographic variables (e.g., age and gender) as well as disease and treatment factors (e.g., administration and complexity) are considered to be poor indicators of medication intake behavior.[4] The treatment of IBD has become more complex since the introduction of immunosuppressive or biological therapy.[5] When their treatments become more complex, patients are more prone to forget how and when they must take their medication.[6] A study measuring patients' knowledge about their immunosuppressive or biological therapy found that of the 354 participating patients, only 60% understood the role of immunosuppressive or biological therapy.[7] Efforts to improve patients' knowledge include the use of information leaflets[8] or physician education.[9] To optimize the initiation process and the implementation or execution process for newly prescribed medication, nurses play an increasingly important role in educating IBD patients about their immunosuppressive or biological therapy during consultations at which medication is prescribed.

These prescribing consultations contain complex and important information about, for example, medication instructions, which are often difficult to remember.[10,11] While information about prescribed medication is important in promoting medication intake behavior, it can be considered to be useless when the recall of medical information, i.e., the ability to understand and reproduce the medical information, is poor.[12,13] In other words, patients who do not know how to take the medication as prescribed because they are not able to understand or reproduce the information are not likely to behave appropriately.[13] Thus, the recall of medical information is expected to influence the quality of the initiation and implementation processes for taking medication. This is in line with Ley's cognitive model, assuming that medication intake behavior can be determined by the recall of medical information.[12] Although the relationship between the actual recall of medical information and medication intake behavior has previously been suggested in the literature,[12] neither

recall has been accurately measured[14,15] nor measured in IBD. When the relationship between medication intake behavior and recall was studied, either recall was measured using only three items[14] or it was assessed many months after the information was provided, both of which make the results less accurate.[15] To improve medication intake behavior and develop target interventions, it is important to understand the relationship between the recall of medical information and medication intake behavior. The aim of this study is therefore to investigate the relationship between the recall of medical information and medication intake behavior in IBD patients by comprehensively measuring the recall of medical information.

2. METHODS

2.1. Design and population

This study was part of a larger study aiming to develop an intervention to tailor the communication to IBD patients' needs and barriers to medication intake behavior. The recommendations for this intervention are based on an investigation of care-as-usual, including patients' recall of medical information and medication intake behavior.
Data were collected from September 2009 until March 2012. Eight IBD nurses at six hospitals participated. Patient inclusion criteria were being diagnosed with Crohn's disease or Ulcerative Colitis according to classical clinical, endoscopic, radiographic and/or pathological histological criteria as determined by an experienced gastroenterologist, starting with Azathioprine, 6-mercaptopurine, Infliximab, Methotrexaat, 6-thioguanine, or Adalimumab, and fluency in Dutch. The Medical Ethical Committee of the VU Medical Center granted permission for this study, which was supplemented with local feasibility statements of all participating hospitals (trial number NTR2892).

2.2. Procedure

Eligible patients were sent a letter with information about the study. Prior to the consultation, a written informed consent was obtained from both the patient and the nurse.
Furthermore, patients completed a written questionnaire containing background information and disease characteristics.
A researcher started a video camera (n = 59) or tape recorder (n = 9) and left the room before the consultation started. Immediately after the consultation, the patients were asked to complete another written questionnaire.
Three weeks after the consultation, the patients were contacted for a telephone interview.

2.3. Measurements

2.3.1. Background characteristics

The background measures included age, gender, level of education, type of disease, years since diagnosis, and administration of the medication (e.g., pills, infusion, or injection).

2.3.2. Content analysis

The information discussed in the videotapes was analyzed using an extensive observation checklist based on comparable studies in oncology.[16,17] The categories in the checklist covered ten primary domains: 'general information about the disease', 'information about the medication', 'side effects', 'information about corticosteroids', 'administration', 'information leaflet', 'recommendations', 'additional necessary medication/checks', 'impact of the medication on patients' daily life', and 'need for blood monitoring'. Each primary domain consisted of several subcategories. The subcategories for the primary domain 'information about the medication' were, for example, 'name of medication', 'duration of the treatment', 'purpose of the treatment', and 'effect of the treatment on patients' health'. Additional subcategories could be added to each primary domain on the checklist.

2.3.3. Recall of medication information

The recall of medical information was measured using an adapted version of The Netherlands Patient Information Recall Questionnaire (NPIRQ), which was originally used in oncology settings and checked against the actual consultation using the observation checklist.[17] For the purpose of this study, the NPIRQ was adapted for the IBD setting. To ensure content relevance, the questionnaire was designed to include questions that were representative of the main topics discussed in the consultations and, at the same time, relevant to patients starting immunosuppressive or biological therapy. We generated questions using pilot observations from videotaped consultations (N = 15). Examples of topics on the questionnaire are as follows: purpose of the medication, name of medication, duration of treatment, frequency of administration, and when to expect an effect from the medication. The content validity of the questionnaire was tested by nine nurses (not involved in the current study). These nurses were asked to indicate topics that, according to them, are discussed in a consultation. Based on their input, the items of the questionnaire were revised or deleted. This review process resulted in thirteen questions, which were assessed directly after the consultation (*immediate recall*). Each question started with a multiple-choice indication of whether the topic was discussed. The answer options were 1) "No, not discussed", 2) "Yes, it was discussed but I don't remember what was said", and 3) "Yes, namely…". With the latter selection, the patient was invited to write down what he or she recalled about the topic (for example, "Can you describe the purpose of the treatment?").
Three weeks after the consultation, *delayed recall* was measured by telephone using thirteen questions. The consultations were analyzed in a naturalistic environment, which meant that the nurses provided some standard introductory information but that the content and the amount of information varied per patient. For this reason, a different version of the delayed questionnaire was developed for each patient based on his or her videotaped consultation. The basis of the questionnaire was the immediate recall questionnaire.
Almost all the questionnaires contained questions about 'the name of the medication', 'what kinds of side effects may occur', 'the frequency of administration' and 'when to contact the nurse'. Topics from that questionnaire that were not or limited discussed were replaced with questions about the most important

other topics discussed in that specific consultation. This resulted in more personal relevant questions (e.g., “What information is given by the nurse about the possibility of getting pregnant when using your medication?” or “What information is given by the nurse about vaccinations when travelling while you are using your medication?”). Two coders first assessed whether the topic was discussed during the visit based on the videotapes. Second, each item recalled was compared with the specific items mentioned by the nurse.[17,18] The percentage of accurate recall was calculated by dividing the sum of the accurately recalled items by the total number of items discussed.[17] Finally, a total recall score was established, which is the mean recall percentage per patient for immediate and delayed recall.

2.3.4. Interobserver reliability

To determine the interobserver reliability of the immediate and delayed recall measurements, two observers randomly coded nine identical transcriptions of the consultations (13%).19 The first author, experienced in coding nurse-patient communication, trained the research assistant in using the observational protocol and coding scheme for the recall questions. After six days of training, the real observations began. Regular meetings were held to discuss and resolve coding issues. Reliability was assessed using Cohen's Kappa, which corrects for agreements due to chance. The mean interobserver reliability was 0.91. For immediate recall, the mean interobserver reliability was 0.85 (Range = 0.72–1) and for delayed recall, the mean interobserver reliability was 0.97 (Range = 0.89–1), illustrating a good interobserver reliability.20

2.3.5. Medication intake behavior

We measured self-reported medication intake behavior with a single item (i.e., “Please indicate on a scale from 1 to 10 the extent to which you are taking the medication as prescribed”, with 1 representing very poor and 10 representing very good). A previous study showed that this self-report measure is significantly related to the scores obtained using a more objective method to measure medication intake behavior: the Medication Event Monitoring System.[21]

2.4. Statistical analysis

A non-response analysis was conducted using t-tests and Chi-square tests to examine the differences between the responders and the non-responders in terms of age and gender. Descriptive statistics were used to describe the sample, the consultation characteristics and the recall scores. The administration of the medication was dummy coded for a regression analysis for ‘injection’ and ‘infusion therapy,’ with ‘pills’ as the reference category. An ANOVA analysis was carried out to compare recall scores between patients taking pills, injections or receiving infusion. A multiple regression analysis was used to examine the predictors of medication intake behavior. The predictors for self-reported medication intake behavior in the regression were pre-selected for each of the patients' demographic variables using a backward selection procedure. In the pre-selection, a significance level of $p = 0.15$ was chosen.[22] Three background characteristics (age, education and type of administration, i.e., injection or infusion therapy) as well as the delayed recall of medical information were retained.

Subsequently, pre-selected variables were included in the final model by entering the following two sets of variables as separate blocks: (i) background characteristics as control variables and (ii) delayed recall of medical information.

3. Results

3.1. Patient characteristics

Of the 100 eligible patients, 22 refused to participate. Nine did not want their consultation to be videotaped, five felt too sick or too tired, and eight felt overwhelmed or were too busy. Another ten patients were excluded because they decided not to start with the prescribed medication.
The non-participating patients did not significantly differ in age or gender from the included patients. The consultations for all remaining patients (N = 68) were analyzed.
Almost two thirds (n = 42) of the sample were female, and 54 patients (79.4%) were diagnosed with Crohn's disease. The mean age was 40.5 years (SD = 14.9), and over half of the patients had received a higher education. A total of 20.6% of the patients received their medication through infusion, 42.6% had to take pills, and 36.8% had to inject themselves (see Table 1).

3.2. Content analysis

The consultations lasted an average of 29.5 min (SD = 8.5).
In all of the consultations, the nurses discussed the side effects (100%). In almost all consultations, the nurses discussed the name of the medication (98.5%) and its administration (97.1%). The medication intake behavior was discussed in 44.1% of the consultations. In almost half of the consultations, the duration of treatment was not discussed (48.5%) (see Table 2).

3.3. Recall of medical information

Patients recalled 52.6% (SD = 15.0) of the information presented by the nurse immediately after the consultation and 53.8% (SD = 15.7) after three weeks. There were no significant differences between the immediate and the delayed recall. The type of information that was most accurately recalled immediately was the administration of the medication; on average, 85.9% of this information was reproduced. Furthermore, 83.6% of the information about the name of the medication was accurately recalled. The information that was reproduced the most poorly was the impact of the medication on the patient's daily life (5.5%), the advice about the medication intake behavior (15.0%) and the potential side effects (26.7%) (see Table 2). An ANOVA analysis showed no significant difference between patients receiving injection, infusion or pills on delayed recall. On average patients using injection recalled (M = 48.2, SD = 12.8) less than patients who received their medication through infusion (M = 59.7, SD = 15.4) or oral medication (M = 51.9, SD = 16.3), however this difference was not significant ($t(66) = 2.27$; p = 0.083).

3.4. Predictors of self-reported medication intake behavior

The patients rated their medication intake behavior on average as 9.1 (SD = 1.2), indicating that most of the patients rated themselves as being quite highly adherent.

[TABLE 1 AND TABLE 2]

Thirty-seven patients (54.4%) rated themselves as completely adherent. Nevertheless, the scores were normally distributed with skewedness and kurtosis below 1.5.[23] The delayed recall ofmedical information was significantly related to the self-reported medication intake behavior ($\beta = 0.37$, $p = 0.007$). This relationship indicates that the patients with lower recall scores three weeks after the consultation rated themselves as less adherent than the patients with higher recall scores. Moreover, the patients who had to inject the medication rated themselves as less adherent compared to those who had to take pills ($\beta = -0.25$, $p = 0.052$) (see Table 3).

After entering the first set of background variables, we found a significant negative relationship between age and self-reported medication intake behavior ($\beta = -0.29$, $p = 0.020$). The relationship between age and medication intake behavior disappeared when controlling for the recall of medical information, implying that there may exist a mediated relationship between age and self-reported medication intake behavior through recall. This mediated effect was tested using Hayes' PROCESS macro.[24] The analysis indeed showed an indirect effect from age on self-reported medication intake behavior through recall. Age was related to recall ($B = -0.44$ $p = 0.000$), and recall was related to self-reported medication intake behavior ($B = 0.02$ $p = 0.03$). The indirect effect of age on self-reported medication intake behavior was significant, 95% CI [−0.024, −0.001], point estimate = −0.009. This result indicates that the older patients are, the less they recall, and the more likely they are to rate themselves as non-adherent.

4. DISCUSSION

This study combines video observations of nurse–patient prescribing consultations about immunosuppressive or biological therapy with post-visit questionnaires to comprehensively measure the recall of medical information. This study investigates the relationship between recall and self-reported medication intake behavior.

Our data support previous research concerning providerpatient communication when prescribing medication.[25–27] The most frequently discussed topics included side effects and the name of the medication. The topics that were often not mentioned were the duration of intake, the advice about medication intake behavior, and the possibility of experiencing side effects. As in a previous study indicating that only 60% of the patients understood the role of immunosuppressive or biological therapy,[7] it appears to be important to train providers to discuss the relevant information necessary to improve their patients' knowledge, which may result in successful medication intake behavior.[9] To the best of our knowledge, this is the first study that measured the recall of medical information in IBD patients extensively. Our results demonstrate that the patients reproduced approximately half of the information provided during consultations. Whether these results are consistent with other studies is difficult to determine. Studies measuring patients' recall of medical information often find inconsistent results, varying in their periods for measuring recall, (unclear) measurements, the type of consultation, and the type of patient.[18] Previous studies in populations with diseases other than IBD reported recall rates ranging from 23% for older cancer patients receiving chemotherapy[17] and 50% for patients receiving health

behavior advice[28] to 86% for patients receiving information about their newly prescribed medication.[29] These findings indicate that our results are within the range of previously reported recall rates.

The information that was recalled most poorly was the impact of the medication on the patients' daily lives. This result is particularly interesting because previous studies have shown that one of the most prevalent information needs of patients receiving new medication is information about its possible impact on their daily life.[30–32] Such personally relevant information is expected to be better recalled.[33] An explanation may be that the patients may not have recognized that the nurses discussed the impact of the medication on their daily life. To improve the recall of medical information, providers should try to explicitly categorize information (e.g., "I am going to tell you how the medication can affect your daily life and how to minimize these effects") since previous research has shown that this is related to an increase in recall.[10] Moreover, information should be categorized into meaningful chunks so that the number of informational items can be reduced.[34,35] The results of this study indicate that the level of recall is a significant predictor for medication intake behavior, thereby supporting Ley's cognitive model. [12] Our results emphasize the importance of patients' recall in promoting medication intake behavior. Previous research also suggested a relationship between recall and patient's medication intake behavior.[14,15] However, the method used to measure recall was limited. We found a relationship between delayed recall and medication intake behavior, but not between immediate recall and medication intake behavior. The explanation might be straightforward. If a patient is not able to correctly remember the information over time, he or she will most likely also not be able to take the medication as prescribed over time. An additional explanation can be found in the recall measurement.

The questions asked after three weeks were particularly developed for each patient based on their videotaped consultation. Thus, those questions could be more related to personally relevant information than the standard recall questions directly after the consultation. This personal information may include barriers for medication intake behavior.

For example, a woman who asks questions about the possibility of becoming pregnant while taking medication is possibly expressing a medication intake barrier. The information given about this barrier is, due to the personal relevance of the topic, expected to lead to deeper processing[33] and, consequently, the higher recall of medical information and better medication intake behavior. This might also explain why there were, on average, no significant differences between immediate and delayed recall, while previous research (e.g., McGuire[36]) found that patients remembered more information immediately after the information provision than after one week and one month.

In contrast to the studies that found that younger patients were more likely to be nonadherent,[37] our findings show that age was negatively related with self-reported medication intake behavior. This result indicates that older patients are more likely to rate themselves as nonadherent.

Indeed, older adults are found to be more prone to misunderstanding medical information due to declines in basic cognitive abilities.[18,38] The majority of the patients were relatively young, which may indicate that the mediated effect of age on self-reported medication intake behavior through recall may be even stronger when studying age differences in a more heterogeneous group with more variance in age.

Our results also show that the necessity of injecting the medications was negatively related to the self-reported medication intake behavior. An explanation for the relation between the necessity of injecting and medication intake behavior may be that injections may cause some degree of discomfort or negative beliefs such as concerns about injection-side pain which may result in higher nonadherence.[39] This difference may explain why patients who had to inject their medication rated themselves as being less adherent compared to those who had to take pills.[39] Our study is limited because the questions varied between the immediate and the delayed recall questionnaires.
Therefore, we were not able to compare scores between immediate and delayed recall. Further research should include standardized educational consultations and questionnaires to compare recall scores.

[TABLE 3]

A self-reported measurement was used to assess medication intake behavior. The many methods used to measure medication intake behavior include physiological/ biomedical measures, refill records, pill counts, or electronic monitoring.
[6,40] Some scholars state that self-reported medication intake behavior can be an accurate measurement[41] and is likely to correlate with more 'objective' measurements.
[21,42,43] In addition, medication intake behavior in this study was measured using one item. Rossiter[44] proposes that if the concept can be conceptualized as concrete and singular, it does not require multiple items to represent it in the measure. Thus, we can assume that the method used to measure the patients' medication intake behavior may be accurate; however, other measurements such as refill data or electronic monitoring may enhance the validity of our findings. Future research should include refill data obtained one year after start to gain more insight into IBD patients' medication intake behavior and to compare the patients' self-reported medication intake scores with more 'objective' methods.
This study indicates that medication intake behavior can be improved if IBD patients are better able to recall the information that they receive. Previous research has shown that patients who received adequate and high-quality information about their prescribed medications were more adherent,[45] which might be partly explained by the higher recall of medical information. This finding implies that communication skills training and guidelines might be useful tools. The Practical and Perceptual Barriers to medication intake behavior typology describes how practical barriers (memory and daily routine barriers) and perceptual barriers (concerns and perceived necessity barriers) can be addressed with tailored communication to promote the recall of medical information and improve medication intake behavior.[46] The results of this study reveal that almost half of the medication information presented by nurses cannot be reproduced by patients and that the patients' recall of medical information is related to medication intake behavior. It is therefore important to consider recall-promoting techniques, such as summarizing, categorizing, or supplementing consultations with written information,[47,48] as a way to improve medication intake behavior.

CONFLICT OF INTEREST

None declared.

ACKNOWLEDGMENTS

We would like to thank all of the nurses and patients that were willing to participate in this study. We also expressly wish to thank Sophie Hafkamp, Gijs Wesseling, Ronald Goeman, Bas Tooms, Silvia Hermanns, Merel Stil and Tessa Bos for their work with regard to data-collection and Dieke Folkeringa for coding the data.

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TABLES

Table 1 Demographic characteristics.

Patient characteristics	N = 68	%
Gender		
Male	26	37.7%
Age		
M (*SD*)	40.5 (*14.9*)	
Type of disease		
Crohn's disease	54	79.4%
Colitis Ulcerosa	13	19.1%
Unknown	1	1.5%
Diagnosed in years		
M(*SD*)	9.6	(*10.3*)
Medication administration		
Infusion	14	20.6%
Pills	29	42.6%
Injection	25	36.8%
Educational level		
Low	18	26.5%
Moderate	24	35.3%
High	26	38.2%
Living arrangements		
Alone	16	23.5%
With partner	16	23.5%
With partner and child(ren)	16	23.5%
With child(ren)	8	11.8%
Other	12	17.6%
Employed		
Yes	51	75.0%
Ethnicity		
Dutch	62	91.2%

Linn, A.J., Dijk, L. van, Smit, E.G., Jansen, J., Weert, J.C.M. van. May you never forget what is worth remembering: the relation between recall of medical information and medication adherence in patients with inflammatory bowel disease. Journal of Crohn's and Colitis: 2013; 7(11), e543-e550

Table 2 Recall scores (N = 68).

Category	No. of items discussed (M)	(SD)	Not discussed [a]	% of consultation in which the topic was not discussed	Recall score [b] (%)	SD
Immediate recall					**52.6**	**15.0**
Purpose of the medication	5.2	1.9	7	10.3	32.7	37.2
Name of medication	0.9	0.3	1	1.5	83.6	37.3
Duration of treatment	0.5	0.5	35	51.5	59.8	43.3
Frequency administration	3.8	3.1	2	2.9	85.9	24.1
Influence of the medication on the immune system	0.8	0.3	8	11.8	69.2	41.1
When to expect an effect from the medication	0.8	0.4	13	19.1	66.8	41.4
The need for blood monitoring	3.3	2.3	13	19.1	63.6	36.6
Side effects	9.0	3.1	0	0	26.7	18.1
When to contact the nurse	3.7	2.2	4	5.9	39.2	30.4
The possibility of experiencing side effects	0.5	0.5	36	52.9	78.8	42.0
The impact of the medication on the patients' daily life	3.6	2.7	14	20.6	5.5	17.9
medication intake behavior advice	0.8	1.1	38	55.9	15.0	32.5
Delayed recall					**53.8**	**15.7**

[a] Number of consultations in which the item was not discussed.
[b] % of correctly recalled information compared with total amount of given information by the nurse, measured only for the consultations in which the category was discussed.

Table 3 Relationship between recall of information and medication intake behavior (N = 68).

	Medication intake behavior				Medication intake behavior			
	Model 1				Model 2			
	B	*SE*	β	*p*	*B*	*SE*	β	*p*
Constant	10.26	0.63			8.6	0.83		
Age	**−0.02**	**0.01**	**−0.29**	**0.020**	−0.01	0.01	−0.15	0.243
Education	−0.01	0.07	−0.01	0.929	−0.06	0.07	−0.09	0.432
Injection [a]	−0.46	0.32	−0.19	0.155	**−0.61**	**0.31**	**−0.25**	**0.052**
Infusion therapy [b]	−0.09	0.38	−0.03	0.802	−0.02	0.36	−0.01	0.952
Delayed recall					**0.03**	**0.01**	**0.37**	**0.007**
Participants	68				68			
R^2	0.09				0.19			
Adjusted R^2	0.04				0.13			
P	0.153				**0.017**			

Bold type indicates which relations were significant.

[a] 0,1; 1 = injection; pills = reference category.

[b] 0,1; 1 = infusion therapy; pills = reference category.