

See “Changes in prevalence and perception of complementary and alternative medicine use in Korean inflammatory bowel disease patients: results of an 8-year follow-up survey” on page 1-8.

Supplementary Material 1. Study Questionnaire (English Version)

Subject Number ()

Prospective study of Complementary and Alternative Medicine Use in Inflammatory Bowel Disease Patients

The current study will be based on responses of this survey which is about the use of complementary and alternative medicine among patients with Ulcerative colitis or Crohn’s disease. This survey will be used only as a basis for research related to the patient’s disease and survey responses will be kept confidential.

Participation in the survey is your freedom and there is no penalty for your care, even if you do not participate in the survey. However, the results of this survey are valuable data for the establishment of medical policy in Korea, which may be beneficial for patients.

Please read through the material and answer the following questions carefully.

What is complementary and alternative medicine?

Complementary and alternative medicine (CAM) is different from conventional medicine. It includes all types of treatment that the patient perceives to be effective for their disease, such as auxiliary roles of herbal medicine, dietary supplements, folk remedies and herbal remedies.

There are several types of complementary and alternative medicine as follows:

Subgroup	Examples
Herbal therapies	Oriental medicine, Red ginseng, Ginseng, Elm leaf, Aloe vera
Nutrition & diet	Royal jelly, Chlorella, Squalene, Chitosan, Fish oil, Propolis, Antler, Dry grain food (Sunsik), Green vegetable juice, Mugwort, Mushroom, Ginkgo, Fermented soybean, Dandelion, Megavitamin, Fasting, Enzyme preparations
Manipulative and body-based medicine	Acupuncture, Hand acupuncture, Bee sting therapy, Cupping, Moxibustion, Massage, Acupressure, Qigong, Lower-body bathing
Folk/traditional medicine	Gaesoju, Black goat soup, Carp soup, Blood of deer
Bioelectronics therapies	Magnetic therapy, Magnetic field therapy
Mind-body medicine	Yoga, Meditation, Prayer, Hypnosis, Tai chi, Biofeedback, Relaxation therapy
Pharmacological and Biological therapies	Shark gristle, Aroma therapy, Neural therapy
Others	Charcoal powder, Placenta injection, Germanium therapy, etc.

1. Which of the following is your diagnosis?
(1) Ulcerative colitis (2) Crohn's disease
2. When was the diagnosis made?
() Year () Month
3. What is your biological sex?
(1) Male (2) Female
4. What is your current age? () years
5. What is your highest level of schooling?
(1) None
(2) Elementary school
(3) Middle school
(4) High school
(5) Completed high school
(6) University
(7) Graduated University or higher
6. Which of the following is your marital status?
(1) Non-married (2) Married (3) Divorced or spouse deceased
7. Do you have a religion?
(1) No (2) Yes (describe specifically:)
8. Do you have an occupation?
(1) No (2) Yes (describe specifically:)
(3) Student (4) Housewife
9. How much is your monthly income?
(1) None
(2) Less than monthly 1 million won
(3) 1 million \leq monthly income < 2 million won
(4) 2 million \leq monthly income < 3 million won
(5) 3 million \leq monthly income < 5 million won
(6) Monthly 5 million won or more
10. How much is the householder's monthly income? (if you're not the householder.)
(1) None
(2) Less than monthly 1 million won
(3) 1 million \leq monthly income < 2 million won
(4) 2 million \leq monthly income < 3 million won
(5) 3 million \leq monthly income < 5 million won
(6) Monthly 5 million won or more

11. Have you been hospitalized for Ulcerative colitis or Crohn's disease?
(1) No (2) 1 time (3) 2 times (4) 3 or more times
12. Have you had surgery related to Ulcerative colitis or Crohn's disease?
(1) No (2) 1 time (3) 2 times (4) 3 or more times
13. Have you used systemic steroids (e.g., prednisone) for your Ulcerative colitis or Crohn's disease?
(1) No (2) Yes
14. Have you used immunomodulators (e.g., azathioprine, purinetone) for your Ulcerative colitis or Crohn's disease?
(1) No (2) Yes
15. Have you ever experienced side effects from medications prescribed for Ulcerative colitis or Crohn's disease??
(1) No (2) Yes
16. How many days have you been symptomatic with Ulcerative colitis or Crohn's disease in the last two weeks?
() days
17. How many outpatient visits did you have during the last 12 months due to Ulcerative colitis or Crohn's disease?
() times
18. How many days have you been hospitalized in the past 12 months because of Ulcerative colitis or Crohn's disease?
() days
19. In the past 12 months, how many days did you have to miss school/work or lie down in hospital/at home because of Ulcerative colitis or Crohn's disease? () days
20. How do you perceive your current health condition?
(1) Well (2) Slightly under par (3) Poor (4) Very poor
21. Have you used complementary and alternative medicine before your diagnosis of Ulcerative colitis or Crohn's disease??
(1) No (2) Yes
22. Have you used complementary and alternative medicine after your diagnosis of Ulcerative colitis or Crohn's disease?
(1) No (2) Yes

*** If you answered no to 22, you do not have to answer questions 23-37. Only answer questions 38 through 44. Write your answers to questions 23 through 25 in the table below.**

23. Indicate all the complementary and alternative medicine currently in use (V) in the table below.
24. Indicate all the complementary and alternative medicine you have used in the last 12 months (V) in the table below.
25. Indicate all the complementary and alternative medicine that have been used since the onset of Ulcerative colitis or Crohn's disease (V) in the table below.

Classification	Types of CAM	23. Currently in use	24. Used in the last 12 months	25. Used since onset of disease
Herbal therapies	Oriental medicine			
	Red ginseng			
	Ginseng			
	Elm leaf			
	Aloe vera			
Manipulative and body-based medicine	Acupuncture			
	Hand acupuncture			
	Bee sting therapy			
	Cupping			
	Moxibustion			
	Massage			
	Acupressure			
	Qigong			
	Lower-body bathing			
Folk/traditional medicine	Gaesoju			
	Black goat soup			
	Carp soup			
	Blood of deer			
Nutrition & diet	Royal jelly			
	Chlorella			
	Squalene			
	Chitosan			
	Fish oil (Omega 3)			
	Propolis			
	Antler			
	Dry grain food (Sunsik)			
	Green vegetable juice			
	Mugwort			
	Mushroom			
	Ginkgo			
	Fermented soybean			
	Flowers (Dandelions, etc.)			
	Megavitamin			
	Fasting			
Enzyme preparations				

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Classification	Types of CAM	23. Currently in use	24. Used in the last 12 months	25. Used since onset of disease
Bioelectronics therapies	Magnetic field therapy			
	Magnet therapy			
Mind-body medicine	Dahnhak gymnastics			
	Yoga			
	Meditation			
	Prayer house			
	Hypnosis			
	Tai chi			
	Biofeedback			
	Relaxation therapy			
Pharmacological and Biological therapies	Shark gristle			
	Aroma therapy			
	Neural therapy			
Others	Charcoal powder			
	Placenta injection			
	Germanium therapy			
Others not mentioned above				

*** Write your answers to questions 26 and 27 in the table below.**

26. Please enter the types of CAM and the appropriate number in the table below for the degree of effect.

- (1) Was very effective
- (2) Was effective
- (3) Not very effective
- (4) Didn't work at all
- (5) Disease rather worsened

Types of CAM	26. Degree of effect	27. Effect duration				
		Lasted less than 1 month	Lasted 1-3 months	Lasted 3-6 months	Lasted 6-12 months	Lasted 12 months or more

34. What were the specific reasons for using complementary and alternative medicine? (You can select multiple answers.)
- (1) To enhance the treatment effect in combination with conventional treatment
 - (2) As CAM is a safe treatment with no side effects
 - (3) As the therapeutic effect of CAM has been proven
 - (4) For psychological stability (the feeling of doing something for my disease)
 - (5) Due to the concern about developing side effects from conventional treatment
 - (6) Because of previous side effects from conventional treatment
 - (7) Because conventional treatment was not effective
 - (8) Because I feel uncertain that conventional treatment will work
 - (9) Because I have a different point of view about the cause and treatment of disease from my physician
 - (10) In order to stop the use of steroids
 - (11) In order to avoid surgery
35. What led you or who introduced you to the use of complementary and alternative medicine? (You can select multiple answers.)
- (1) My own opinion
 - (2) Recommendation by friends or family
 - (3) Recommendation by other patients
 - (4) Through information from IBD patient meetings
 - (5) Through information from the media (newspaper, broadcast, magazines)
 - (6) Through information from the internet
 - (7) Recommendation from a pharmacist
 - (8) Recommendation from a physician
 - (9) Others (describe specifically: _____)
36. How much did you spend on complementary and alternative medicine in the last 12 months?
(_____) won
37. Is the cost of complementary and alternative medicine appropriate?
- (1) It is a burden (2) It is affordable
38. What was the total cost of conventional treatment for Ulcerative colitis or Crohn's disease (including the cost of clinic visits, tests/procedures, hospitalization, surgery, and prescription drugs) over the past 12 months?
(_____) won
39. What is your opinion in terms of the effectiveness of conventional treatment and complementary and alternative medicine?
- (1) Conventional treatment is more effective than CAM
 - (2) CAM is more effective than conventional treatment
 - (3) Conventional and CAM have similar effects
 - (4) I am not sure
40. What is your opinion in terms of the side effects of conventional treatment and complementary and alternative medicine?
- (1) Conventional treatment has more side effects than CAM
 - (2) CAM has more side effects than conventional treatment
 - (3) Conventional treatment and CAM have degree of side effects
 - (4) I am not sure

41. What is your opinion in terms of the cost of conventional treatment and complementary and alternative medicine?
- (1) Conventional treatment is more expensive than CAM
 - (2) CAM is more expensive than conventional treatment
 - (3) Both are similar in terms of cost
42. What is your opinion in terms of the reliability of conventional treatment and complementary and alternative medicine?
- (1) I trust conventional treatment more than CAM
 - (2) I trust CAM more than conventional treatment
 - (3) Both are similar in terms of reliability
43. Are you willing to use complementary and alternative medicine in the future?
- (1) I have never used it before, and I do not intend to use it in the future
 - (2) I have not used it yet, but I am thinking about using it in the future
 - (3) I have used it but I do not intend to use it in the future
 - (4) I have used it and I think I will use the same type in the future
 - (5) I have used it and I am thinking about using a different type in the future
44. If you have never used complementary and alternative medicine, why? (Only answer if you have never used CAM.)
(You can select multiple answers.)
- (1) Because conventional treatment is effective
 - (2) For fear that CAM may adversely affect conventional treatment
 - (3) Because my physician did not recommend CAM (or recommended against CAM)
 - (4) Because I do not know about CAM
 - (5) Because I do not have confidence in the effects of CAM
 - (6) Because CAM has no scientific evidence
 - (7) Because I am concerned of developing side effects from CAM
 - (8) Because of the cost of CAM
 - (9) Because CAM is not accessible and is not easy to find

***Answer questions 44 and 45, only if you have been seen by an oriental doctor (naturopath) for Ulcerative colitis or Crohn's disease.**

45. What was the oriental doctor's view on the treatment of Ulcerative colitis or Crohn's disease?
- (1) The disease can be treated with oriental medicine
 - (2) Oriental medicine may improve symptoms, but cannot treat the disease
 - (3) The disease cannot be treated with oriental medicine; therefore see a physician for appropriate conventional treatment
 - (4) Others (describe specifically: _____)
46. What was the oriental doctor's view on the use of conventional treatment for Ulcerative colitis or Crohn's disease??
- (1) I was told to stop conventional treatment while taking oriental medicine
 - (2) I was told to continue taking conventional treatment while taking oriental medicine
 - (3) Others (describe specifically: _____)

- Thank you -