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Chasm between Public Perceptions and Epidemiological Data on Colorectal Cancer

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Background/Aims: Only a few studies have examined perceptions of the incidence and prognosis of colorectal cancer (CRC) in the general Korean population. The aim of this study was to determine public perceptions of the lifetime incidence rate and survival of CRC.

Methods: All adults older than 50 years who visited the Kyung Hee University Hospital at Gangdong were invited to participate in this survey for 5 months in 2021. During the study period, eligible individuals participated in this survey through a link or quick response code on a poster posted in the hospital, which was linked to a web-based questionnaire. The questionnaire used for this survey included demographic and socioeconomic data, perceptions of CRC, and awareness of the CRC incidence and 5-year survival rate.

Results: Among 203 respondents, 196 answers were analyzed after the exclusion of seven incomplete answers. In our survey, half of the respondents (49.5%) answered the expected lifetime incidence rate of CRC as 0% to 4.9%. Koreans perceived CRC as a more fatal disease than epidemiological data, as 70.9% of the respondents expected the 5-year survival rate of CRC to be less than 70% for the general population. However, Koreans perceived stage IV CRC as a less fatal disease than epidemiological data, because only 20.9% of the respondents expected the 5-year survival rate of stage IV CRC to be less than 10% for general population.

Conclusions: Koreans recognized CRC as a more common and fatal disease than actual epidemiological data of CRC. Therefore, more efforts should be made to provide more correct information on CRC for better decision-making and communication. (*Gut Liver* 2023;17:449-455)

Key Words: Colorectal neoplasms; Perception; Prognosis; Screening; Survival

INTRODUCTION

Colorectal cancer (CRC) is a significant public health problem, and its incidence has been increasing worldwide including South Korea.^{1,2} CRC screening can decrease CRC incidence and mortality through early detection and removal of colorectal neoplasia.³⁻⁶ Recently, the number of CRC screening in the elderly population has dramatically increased with increasing life expectancy.⁷ Therefore, the potential benefits of CRC screening need to be balanced against their competing risks, especially in case of colonoscopy screening of elderly individuals. Recently, clinicians are increasingly faced with the prospect of having to consult CRC screening in the elderly population. Most guide-

lines recommend that colonoscopy screening is generally not advised for the very elderly (>76 years) individuals,^{8,9} however, few guidelines mention the upper age limit for fecal occult blood test (FOBT). Up to date, little is known for the expected upper age limit of CRC screening, for FOBT and colonoscopy in the public.

Generally, cancer is regarded as one of the most feared diseases for the public.^{10,11} As risk perception of cancer plays an important role in participating in cancer screening, optimal public perception of CRC risk is important but it may be subjective and biased. Incorrect perception of CRC incidence and prognosis may affect CRC screening and treatment.^{12,13} Until now, however, only one study has examined perceptions of the incidence and prognosis



of CRC for Koreans.¹⁴ However, this study had an important limitation as it included all cancers and not focused on CRC, so additional study focused on CRC is necessary. In addition, previous study was also limited as only few elderly patients participated in the survey because the median age was 52 years (interquartile range, 46 to 58 years). Therefore, this kind of survey should be performed including many elderly patients, who are an important target of CRC screening, using a CRC-focused questionnaire.

The aim of this study was to determine public perceptions of lifetime incidence rate and survival for CRC for individuals over 50 years old.

MATERIALS AND METHODS

1. Study participants

All adults over the age of 50 who visited Kyung Hee University Hospital at Gangdong were invited to participate in this survey between August 4, 2021, and December 24, 2021. We decided to target participants as 50 years of age or older because young adults under age of 50 may have the low participation rate due to less interest for the CRC, and they are CRC screening candidate group as CRC screening begins at the age of 50. During study periods, eligible individuals participated in this survey through a link or quick response code on a poster posted in the hospital, which was linked with web-based questionnaire. The survey tool was made using a commercial survey program (SurveyMonkey, www.surveymonkey.com). This survey took approximately 6 to 7 minutes, and no incentives were provided to improve the survey response. The participants were informed for voluntary and anonymous participation and the study's rationale and objectives. Informed consent was waived for this online-based survey, as it was collected anonymously without personal information. Survey results were excluded from analysis if answers were incomplete or participants were younger than 50 years. The Institutional Review Board of Kyung Hee University Hospital at Gangdong approved this study (KHNMC IRB number: 2021-06-033).

2. The questionnaire

The questionnaire used for the survey explored the following areas: (1) demographic and socioeconomic data, including age, sex, education level, marital status, ever diagnosis of CRC, alcohol drinking, smoking, exercise, and household incomes; (2) awareness on CRC incidence, including life expectancy, healthy life expectancy, expected lifetime incidence rate of CRC, expected upper age limit for CRC screening and treatment; (3) awareness on CRC

prognosis, including expected 5-year survival rate (5YSR) of all CRC and stage IV CRC; and (4) perceptions for CRC, including subjective perception for health status, ever screening of CRC, personal risk factor of CRC, and personal effort to prevent CRC. Questionnaires for the life expectancy, healthy life expectancy, expected 5YSR of CRC and stage IV CRC were surveyed for general Koreans and participants themselves. These questions were asked for general Koreans and participants themselves as survey participants could think differently about their own and Koreans' perception by their own health status or comorbid diseases. Alcohol drinking was defined as alcohol consuming more than 1 drink on any day per week, and smoking was defined as more than 5 packs during a lifetime. Exercise was defined as a moderate-intensity exercise,¹⁵ such as bicycling light effort, badminton recreational, tennis doubles or cleaning heavy with vacuuming for washing windows. Household incomes were classified into deciles based on income based on a family of four in 2021. We asked the participants for perception of the lifetime CRC incidence rates themselves with the following question: "If you survive to life expectancy, how would you estimate your likelihood of being diagnosed with CRC in your lifetime?" Participants answered the question by five votes among (1) 0%–4.9%, (2) 5%–9.9%, (3) 10%–14.9%, (4) 15%–19.9%, and (5) ≥20%. To assess perceptions of the 5YSR of CRC, we asked participants the following question: "How would you estimate the likelihood of 5YSR after being diagnosed with CRC?" Participants answered the question by 10 votes among (1) <0%–10%, (2) 11%–20%, (3) 21%–30%, (4) 31%–40%, (5) 41%–50%, (6) 51%–60%, (7) 61%–70%, (8) 71%–80%, (9) 81%–90%, and (10) 91%–100%. In order to avoid bias due to the answer branch, 10 votes with a 10% interval were provided. Perceptions of 5YSR were questioned for both all CRCs and stage IV CRCs, respectively.

3. Statistical analyses

The demographic and sociological characteristics of the study participants were summarized using descriptive statistics. Continuous variables were expressed as mean±standard deviation, and categorical variables were presented as numbers and percentages. Statistical analysis was performed by using the Statistical Package for the Social Sciences (SPSS) version 18.0 for Windows (SPSS Inc., Chicago, IL, USA).

RESULTS

1. Demographic and socioeconomic characteristics

Two hundred three participants completed the survey,

and 196 answers were analyzed after exclusion of seven incomplete answers. Table 1 shows the demographic and socioeconomic characteristics of respondents. The mean age was 64.6 ± 8.2 years and 91.3% of them ranged in the 50 to 75 years age group, which are a target age group for CRC screening. In total, 111 respondents were male (56.6%), 121 were non-alcoholics (61.7%), and 117 were non-smokers (59.7%). In addition, 13 of them (6.6%) had a personal history of CRC.

2. Public perception on CRC incidence

Table 2 shows the public perceptions on CRC. Respondents expected life expectancy for general Koreans as 87.6 years, but slightly shorter life expectancy for themselves. For the healthy life expectancy, respondents expected life expectancy for general Koreans as 80.9 years, but slightly longer life expectancy for themselves. Koreans recognized CRC as a more common disease, as only 49.5% of respondents expected 0% to 4.9% lifetime incidence of CRC compared with the actual 1% to 4% lifetime incidence of CRC

Table 1. Demographic and Socioeconomic Characteristics

Characteristic	Results (n=196)
Age, yr	64.6±8.2
Age group, yr	
50–65	101 (51.5)
66–75	78 (39.8)
76–85	15 (7.7)
≥86	2 (1.0)
Sex	
Male	111 (56.6)
Female	85 (43.4)
Education level	
≤High school	84 (42.9)
College or above	112 (57.1)
Marital status	
Married	178 (90.8)
Single or others	18 (9.2)
Alcohol drinking	
No	121 (61.7)
Yes	75 (38.3)
Smoking	
No	117 (59.7)
Ex-smoker	59 (30.1)
Current smoker	20 (10.2)
Ever diagnosis of colorectal cancer (yes)	13 (6.6)
Exercise (moderate-intensity)/wk	
Less than 2 day	114 (58.2)
More than 3 day	82 (41.8)
Household income	
1–4 decile	103 (52.6)
5–10 decile	93 (47.4)

Data are presented as mean±SD or number (%).

in epidemiological data (Fig. 1). For the expected upper age limit for CRC screening, upper age limit was approximately 80 years and similar for FOBT and colonoscopy. For the expected upper age limit for CRC treatment, upper age limit was approximately 81 years and similar for surgery and chemotherapy.

3. Public awareness for CRC prognosis

Table 3 shows the public awareness of CRC prognosis. Koreans perceived CRC as a more fatal disease than epidemiological data, because 70.9% of respondents expected

Table 2. Public Perception of CRC

Survey for CRC screening	Results
Life expectancy, yr	
General Koreans	87.6±8.6
Oneself	85.7±6.0
Healthy life expectancy, yr	
General Koreans	80.9±8.7
Oneself	83.0±8.7
Expected lifetime incidence rate of CRC, %	
0–4.9	97 (49.5)
5–9.9	34 (17.3)
10–14.9	36 (18.4)
15–19.9	13 (6.6)
≥20	16 (8.2)
Expected upper age limit for CRC screening, yr	
With fecal occult blood test	80.7±7.3
With colonoscopy	80.0±7.1
Expected upper age limit for CRC treatment, yr	
With surgery	81.7±6.0
With chemotherapy	81.3±6.5

Data are presented as mean±SD or number (%).
CRC, colorectal cancer.

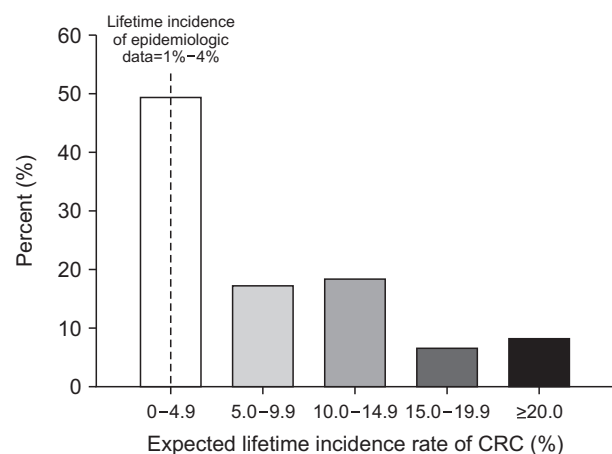


Fig. 1. Expected lifetime incidence of colorectal cancer (CRC). Only 49.5% of the respondents expected a 0% to 4.9% lifetime incidence of CRC compared with the actual 1% to 4% lifetime incidence of CRC.

5YSR of CRC as less than 70% for general Koreans (Fig. 2). On the contrary, Koreans perceived stage IV CRC as a less fatal disease than epidemiological data, because only 20.9% of respondents expected 5YSR of stage IV CRC as less than 10% for general Koreans (Fig. 3).

4. Health behavior for CRC

For the subjective perception of health status, 64.3%

of participants answered that they are very or relatively healthy (Table 4). For the ever screening of CRC, 55.1% of participants experienced both FOBT and colonoscopy, 31.1% of them experienced colonoscopy only, 6.6% of them experienced FOBT only, and only 7.1% of them experienced no screening of CRC. For the personal risk factor of CRC, 54.1% of respondents reported more than one risk factor of CRC; lack of exercise, obesity in 18.4%, low fiber diet, animal fat, or red meat in 11.7%, smoking or

Table 3. Public Awareness of CRC Survival

Survey on CRC survival	No. (%)
Expected 5-yr survival rate of CRC, %	
For general Koreans	
<30	20 (10.2)
30-50	32 (16.3)
51-70	87 (44.4)
>70	57 (29.1)
For oneself	
<30	33 (16.8)
30-50	39 (19.9)
51-70	69 (35.2)
>70	55 (28.1)
Expected 5-yr survival rate of stage IV CRC, %	
For general Koreans	
<10	41 (20.9)
10-20	22 (11.2)
21-30	37 (18.9)
>30	96 (49.0)
For oneself	
<10	38 (19.4)
10-20	22 (11.2)
21-30	41 (20.9)
>30	95 (48.5)

CRC, colorectal cancer.

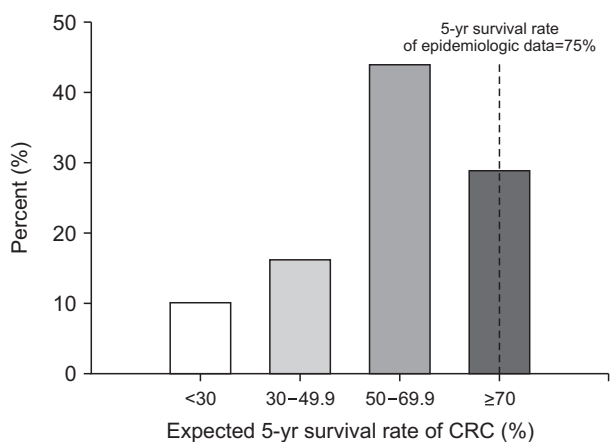


Fig. 2. Expected 5-year survival rate of colorectal cancer (CRC). Pessimistically, 70.9% of the respondents expected that the 5-year survival rate of CRC will be less than 70% for the general Korean population as compared with the actual 75% 5-year survival rate of CRC in epidemiological data.

Table 4. Health Behavior for CRC

Demographic characteristics	No. (%)
Subjective perception for health status	
Very or relatively healthy	126 (64.3)
I don't know	31 (15.8)
Relatively or very unhealthy	39 (19.9)
Ever screening of colorectal cancer	
None	14 (7.1)
Fecal occult blood test	13 (6.6)
Colonoscopy	61 (31.1)
Both fecal occult blood test and colonoscopy	108 (55.1)
Personal risk factor of colorectal cancer	
No risk factors	90 (45.9)
Low fiber diet, animal fat, or red meat	23 (11.7)
Lack of exercise, obesity	36 (18.4)
Smoking, alcohol drinking	22 (11.2)
Family history of colorectal cancer	15 (7.7)
Inflammatory bowel disease	10 (5.1)
Personal effort to prevent colorectal cancer	
No effort	64 (32.7)
High-fiber diet	30 (15.3)
No smoking and drinking	4 (2.0)
Regular exercise, maintaining proper weight	33 (16.8)
Regular colorectal cancer screening	65 (33.2)

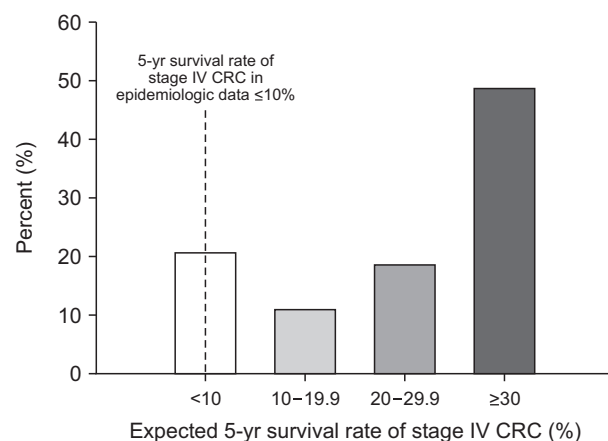


Fig. 3. Expected 5-year survival rate of stage IV colorectal cancer (CRC). Koreans perceived stage IV CRC as a less fatal disease than epidemiological data, as only 20.9% of the respondents expected that the 5-year survival rate of stage IV CRC will be less than 10%.

alcohol drinking in 11.2%, family history of CRC in 7.7%, and inflammatory bowel disease history in 5.1%. For the personal effort to prevent CRC, however, 32.7% of them showed no effort. Fortunately, 33.2% of them reported regular CRC screening, 16.8% reported regular exercise and maintaining proper weight, 15.3% reported a high-fiber diet, and 2% reported no smoking and no drinking.

DISCUSSION

To the best of our knowledge, this is the first study that provides a valuable overview of public perceptions regarding CRC incidence and prognosis. According to the GLOBOCAN report, the lifetime risk of developing CRC is 4.1% of all Americans,¹⁶ and it is 1.5% for men and 1.1% for women.¹⁷ In our survey, only a half of respondents (49.5%) had a correct perception for the expected lifetime incidence rate of CRC, and the other half of them perceived the lifetime incidence rate of CRC to be much higher than the actual epidemiological data.^{16,17} Our findings were in contrast to those from Japan,¹⁸ as the lifetime incidence rates of CRC were expected to be much lower than epidemiological data as more than 90% of respondents underestimated lifetime incidence rate of CRC. Americans, similarly, perceived the lifetime incidence rate of cancer to be much lower than the epidemiological data.¹⁹ For example, U.S. survey revealed that 50% of people surveyed believed that their lifetime cancer risk was less than 1%, whereas only 15% believed that their risk was $\geq 20\%$.¹⁹ This national difference may be explained by that Koreans are more exposed to CRC-related information via the mass media or the Internet than Japanese or Americans. Higher expectation of lifetime risk of CRC could explain the higher rate of ever screening of CRC and only 7.1% of no screening of CRC in our survey.

Our survey showed that Koreans do not correctly estimate the prognosis of CRC. In a recent data from the Korea Central Cancer Registry, 5YSR of all CRCs was 75.0% from 2011 to 2015.²⁰ However, only 28.1% to 29.1% of participants expected 5YSR of all CRCs will be over 70% for general Koreans, and about 70% of Korean public perceives the 5YSR of all CRCs more pessimistically than the real epidemiological data (Fig. 2). In addition, the 5YSR for stage IV CRC was less than 10% in epidemiological data.²¹ In our survey, only 20.9% to 19.4% of participants expected 5YSR of stage IV CRCs to be less than 10% for general Koreans, and about 80% of Korean public perceives the 5YSR of stage IV CRCs more optimistically than the real epidemiological data (Fig. 3). In previous studies, Japanese¹⁸ and Americans^{22,23} also showed incorrect esti-

mate on cancer prognosis similar to our survey results. A pessimistic view of prognosis on all CRCs and an optimistic view of prognosis on stage IV CRC might interfere with an optimal decision about CRC screening and treatment. For example, a pessimistic view of prognosis for all CRC reduced the motivation to participate in CRC screening,²³ and an optimistic view of prognosis on stage IV CRC may decrease the opportunity for optimal treatment. Therefore, our findings underscore the importance of accurately understanding public perceptions, which may need public education on the prognosis of CRC.

The U.S. multi-society task force strongly recommends CRC screening for individuals between ages 50 and 75 and discontinuation of screening for those between ages 76 and 85.⁹ In a population-based study from Korea,⁷ 107,972 colonoscopies (5.1% of total colonoscopies) were performed for very elderly (>76 years) individuals in 2013. Common practice of colonoscopy for the very elderly individuals in Korea may be explained by our survey findings that upper age limit for CRC screening was expected to 80 years for both of FOBT and colonoscopy. Therefore, colonoscopy for very elderly individuals should be discussed for their risks and benefits, based on their age and comorbidities, with shared decision making. In our survey, 54.1% of respondents reported at least more than one risk factor of CRC, however, 32.7% of them showed no personal effort to prevent CRC. Primary prevention of CRC by risk factor modification as well as screening could reduce 10% to 54% of CRC incidence.²⁴ Therefore, more promotion and education on risk factor modification as well as screening of CRC are likely to be necessary.

In a recent review, non-modifiable factors such as age, sex, race, marital status, education level, and family history of CRC, and modifiable factors such as health seeking behavior, attitudes and knowledge about CRC were suggested as factors that influence adherence of CRC screening.²⁵ The first step to improve public perceptions and adherence to improve CRC screening is education and engagement of public for CRC screening with system-based approach. For example, a centralized mailed program with stepped increases of support increases 31% more adjusted time in compliance with CRC screening guidelines over 5 years in the United States.²⁶ It is necessary to use pamphlets, brochures, newsletters, television and social media to raise public awareness and change their attitudes on CRC screening to engage the public.²⁵ A recent systematic review and meta-analysis showed a pooled odds ratio of 1.5 in promoting cancer screening participation using social media and mobile health interventions.²⁷ During the coronavirus disease 2019 pandemic, "Twitter" was also suggested as an effective strategy to better understand public com-

munication and perceptions of CRC.²⁸ Recently, the role of social media in raising public awareness on CRC screening is increasing, so it could be a cost-effective approach. Finally, reduction of structural barrier to CRC screening is useful in increasing CRC screening participation rate.²⁵ In rural areas of South Korea, for example, round-mailed FOBT kit with phone call reminders increased CRC screening participation rate from 24.5% to 51.4%.²⁹

We concede that one of the limitations of this study is that our survey participants were not a representative sample of general Koreans. In this survey, however, all adults over the age of 50, including outpatient and their companions, hospital staff, and others, participated. In addition, it is not known how many outpatients participated in this survey as it was not conducted by face-to-face survey, but, by a link or quick response code on a poster posted in the hospital. It is also another limitation of this study as public perception on CRC may be affected by the comorbidities of the survey participants. Another limitation of this survey is a relatively small sample size, which may limit a generalization of our findings.

In conclusion, our findings showed that Koreans recognized CRC as a more common and fatal disease and stage IV CRC as a less fatal disease than epidemiological data. Therefore, there is a chasm between public perceptions and epidemiological data regarding the incidence and prognosis of CRC. We believe that our findings have important clinical implications for the strategy of screening and treatment of CRC. Therefore, more efforts should be paid to provide more correct information on CRC for better decision-making and communication.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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AUTHOR CONTRIBUTIONS

Study concept and design: J.M.C. Data acquisition: S.B.P.

Data analysis and interpretation: M.S.K. Drafting of the manuscript: J.Y.Y. Critical revision of the manuscript for important intellectual content: J.M.C. Statistical analysis: J.M.C. Obtained funding: J.M.C. Administrative, technical, or material support; study supervision: S.B.P., J.M.C. Approval of final manuscript: all authors.

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