

Fear of cancer recurrence in colorectal cancer survivors

José A. E. Custers¹ · Marieke F. M. Gielissen¹ · Stephanie H. V. Janssen² · Johannes H. W. de Wilt² · Judith B. Prins¹

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Abstract

Purpose Although long-term colorectal cancer (CRC) survivors generally report a good quality of life, fear of cancer recurrence (FCR) remains an important issue. This study investigated whether the Cancer Worry Scale (CWS) can detect high FCR, the prevalence, and characteristics of FCR in CRC survivors.

Methods Two hundred and eleven patients who had undergone successful CRC surgery in the period 2003–2010 in the Radboud University Medical Center in the Netherlands were asked to participate. All patients were sent an information letter plus questionnaires for collecting information on demographic and medical variables, FCR, distress, and quality of life.

Results Seventy-six patients (36 %; median age of 67.7 years range 41–88 years) completed the questionnaires a median of 5.1 years after surgery. A cut-off score of 14 or higher on the CWS was optimal to detect high FCR. Twenty-nine patients (38 %) experienced high levels of FCR, characterized by higher levels of distress, post-traumatic stress symptoms, and lower quality of life. These individuals particularly reacted to disease-related triggers, felt helpless, were worried, and experienced limitations in daily functioning. High FCR was not associated with demographic or medical variables.

Conclusion Long after successful CRC surgery, FCR is a serious problem that impairs the quality of life for a substantial proportion of patients. With the CWS, it is possible to detect high FCR and thereby assist survivors in receiving appropriate care.

Keywords Fear of cancer recurrence · Quality of life · Colorectal cancer · Oncology

Introduction

Early detection and improved cancer treatment have increased the survival rate of colorectal cancer (CRC) over the past decades [1]. This has made it important to pay attention to the way survivors deal with chronic or late effects of the disease and its treatment. A number of recent studies have investigated the quality of life (QoL) of CRC survivors and have shown that while QoL is reduced after treatment completion, it gradually improves over time in the absence of disease recurrence or progression [2–5]. While a systematic review found long-term CRC survivors to have good overall QoL [6], this does not necessarily mean that these individuals do not experience problems that can influence their daily functioning. Not only can CRC survivors have specific physical complaints, such as fecal, urinary, or sexual disorders [7], but they might also have an unmet need for psychosocial help with regard to fear of cancer recurrence (FCR) [8]. FCR can be defined as the fear or worry that the disease will return or progress in the same organ or in another part of the body [9]. While a normal level of FCR can keep a person alert and aware of symptoms [10], high levels of FCR can adversely affect a person's quality of life and social activities [11–14].

✉ José A. E. Custers
Jose.Custers@radboudumc.nl

¹ Department of Medical Psychology 840, Radboud University Medical Center, PO Box 9101, 6500 HB Nijmegen, The Netherlands

² Department of Surgery 618, Radboud University Medical Center, PO Box 9101, 6500 HB Nijmegen, The Netherlands

Patients may focus obsessively on symptoms [10], which can restrict their ability to plan for the future and can lead to numerous unscheduled doctor appointments [15, 16]. Among the few studies reporting FCR in CRC survivors, the prevalence of high FCR ranges between 4 and 85 % [17–22]. This wide range of percentages high FCR might be attributed to the fact that there is no consensus about what are clinically relevant levels of FCR. Furthermore, it might be attributed to the use of various instruments to measure FCR for which there are few or no psychometric data or cut-off points available [10]. In the research on FCR in CRC patients, some studies did not use a FCR specific measure [18, 21], whereas others had lacking data on validity [17, 19, 20]. Therewith, interpretation and comparison of percentages high FCR is difficult. Recently, a semi-structured interview to identify patients with clinical levels of FCR was developed by Simard and Savard [22]. Based on this interview, cut-off scores on the severity subscale of the Fear of Cancer Recurrence Inventory (FCRI-SF) were determined. Therewith, it is possible to use this scale as gold standard measure for evaluating the criterion validity of different FCR scales. The aim of this study is to assess the capacity of the Cancer Worry Scale (CWS), validated in a sample of breast cancer survivors [23], as an instrument to detect high levels of FCR in a sample of CRC survivors. Furthermore, there has been little research on FCR in CRC survivors, its characteristics, and potential risk groups, mainly because earlier studies focused on the severity and prevalence of FCR. There is a lack of information about what specific triggers make survivors fearful, which strategies they use to cope with this fear, and the concrete consequences of FCR in daily life. This study focuses on the prevalence and characteristics of FCR in CRC survivors.

Methods

Participants

In March 2012, participants were recruited from the Department of Surgery, Radboud University Medical Center, Nijmegen in the Netherlands. CRC survivors who had been treated with curative intent and who were disease-free (no recurrence or metastases) 1–9 years after surgery were eligible for inclusion. Participants had to be able to read and write in Dutch.

Procedure

Documented approval from the local Medical Ethics Committee was obtained prior to start of the study. Contact data of CRC survivors were obtained by a surgeon (JW), and these individuals were sent a letter describing the purpose of the study and a booklet with questionnaires on demographic variables and psychological factors. Participants gave their

informed consent by returning the booklet. Clinical data were extracted from medical records by one of the researchers (SJ).

Instruments

Fear of cancer recurrence: severity

The CWS is used in research to assess concerns about developing cancer or developing cancer again and the impact of these concerns on daily functioning. The eight items of the CWS are rated on a 4-point Likert scale ranging from “Never” to “Almost always”. Scores range from 8 to 32 [24]. A diagnostic cut-off score of 14 or higher (sensitivity 77 %; specificity 81 %) was validated for breast cancer survivors and indicates raised levels of FCR [23].

Fear of cancer recurrence: multidimensional aspects

The Fear of Cancer Recurrence Inventory (FCRI) was developed to assess the multidimensional aspects of FCR. The FCRI consists of seven subscales: triggers, severity, psychological distress, coping strategies, functioning impairments, insight, and reassurance. The 42 items are rated on a 5-point Likert scale ranging from 0 to 4. The FCRI is a reliable and valid self-report scale [25].

The subscale *Triggers* includes eight items, of which seven assess specific situations that make one think about the possibility of cancer recurrence; one item assesses to what degree these situations are generally avoided. The subscale *Severity* includes nine items assessing the presence, frequency, intensity and duration of thoughts associated with FCR, the perceived risk of recurrence, the legitimacy of worrying about cancer recurrence, and the presence of other unpleasant thoughts or images that come to mind in association with FCR. Recently, data were provided that this subscale may also be used as FCRI-short form to screen for clinical levels of FCR. A score of 13 or higher was optimal for screening whereas a score of 16 or higher was the optimal diagnostic cut-off [22]. The subscale *Psychological Distress* includes four items for emotions frequently triggered by thoughts about cancer recurrence. The subscale *Coping Strategies* assesses nine strategies that may be used to cope with FCR including denial, wishful thinking, or cognitive avoidance.

The subscale *Functioning Impairments* includes six items representing domains that can be disturbed by FCR. The subscale *Insight* includes three items and assesses the extent to which patients perceive their fear as excessive or unreasonable. The subscale *Reassurance* includes three items representing reassurance behaviors specific to FCR.

Distress: cancer-specific

The Impact of Event Scale (IES) was included to assess the frequency of intrusive and avoidant phenomena after or during the traumatic experience of cancer. Its 15 items (scoring 0, 1, 3, 5) are divided into two dimensions: “Intrusion” (7 items) and “Avoidance” (8 items). A total score of 9–25 reflects moderate adaptation difficulties; a score higher than 26 indicates serious adaptation difficulties [26, 27].

Distress: general

General distress was measured with the total score of the Hospital Anxiety and Depression Scale (HADS). This questionnaire includes 14 items divided into two subscales (Depression and Anxiety), each with seven items. Higher scores indicate more anxiety, depression, and psychological distress. The HADS does not contain any somatic items that could be confounded with symptoms associated with a physical illness. A total score of 11 or higher indicates high distress [28, 29].

Quality of life: cancer-related

Quality of life related to CRC was measured with the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 30 (QLQ-C30) and Colorectal Cancer Module (QLQ-CR38). In this study, only scores for the functional scales and global health scale were analyzed. Higher scores on functional scales indicate better functioning and quality of life. All scores are transformed linearly and range from 0 to 100 [30, 31]. A difference of 5–10 points was considered small, 10–20 points medium and >20 points large [32].

Data-analyses

Prior to SPSS (version 20.0) data analysis, all relevant data were screened for normality and showed normal distributions. Means and frequencies were used to describe the sample. Only complete data for the CWS were analyzed; incomplete data were recorded as missing data and excluded from the analyses. Receiving operating characteristics (ROC) analysis was conducted to evaluate the performance of the CWS by providing information relevant to the full range of scores that need to be taken into account in making a threshold for high FCR in a population of CRC survivors. The accuracy properties sensitivity, specificity, and positive and negative predictive values were assessed at each cut-off point of the CWS against the FCRI-SF. Furthermore, the area under the ROC curve and its 95 % confidence interval were examined. To differentiate high FCR from low FCR, an optimal cut-off point should have high sensitivity and specificity, which maximizes the proportion of patients whose test results are accurate [33].

Multivariate ANOVAs were performed for continuous variables, to assess differences between high and low FCR, based on the cut-off score (low ≤ 13 ; high ≥ 14). Chi-square analyses were performed to assess differences between high and low FCR with regard to categorical variables. Pearson product moment correlations and independent sample *t* tests were used to assess relations between continuous variables.

For a descriptive analysis of the FCRI scores, percentages of responses to the individual questions were calculated. In order to reflect the degree of involvement with a specific item, varying from small to moderate or large, answers on the subscales Triggers, Coping, and Reassurance were combined into three answer categories: (1) “never/rarely”, (2) “sometimes”, and (3) “most of the time/all the time”. Answers on the subscales Severity, Psychological Distress, Functioning Impairments, and Insight were also divided into three answer categories: (1) “not at all/a little”, (2) “somewhat”, and (3) “a lot/a great deal”.

Results

Sample characteristics

Of 211 CRC survivors asked to participate in the study, 80 (38 %) returned the questionnaires, and 76 (36 %) of whom completed the CWS and were included in the analyses. There was no difference between responders and non-responders with regard to gender ($\chi^2(1, 211)=0.03, p=0.87$), but non-responders were significantly older ($t(209)=2.0, p=0.046$). Table 1 shows the demographic and medical characteristics of the responders.

ROC analysis

The area under the curve of the ROC analysis showed a 92 % ($p<0.001$; 95%CI=0.85–0.98) probability that a randomly selected patient defined as a case by the FCRI-SF (≥ 16) scores higher on the CWS than a randomly selected patient defined as a non-case (Fig. 1). On the basis of the ROC curve, the optimal cut-off score to differentiate between high FCR and low FCR was 13 versus 14 (low ≤ 13 , high ≥ 14), with a sensitivity of 86 % and a specificity of 87 %. The positive and negative predictive values were 76 and 93 %, respectively (Table 2).

Reliability and measure of agreement

The CWS yielded a high internal consistency reliability coefficient, Cronbach $\alpha=0.89$. The correlation between the CWS and FCRI-SF was $r=0.85$. In 87 % of the cases, there was agreement between the CWS and FCRI-SF concerning the

Table 1 Sample characteristics ($n=76$)

Age (years)	Median 67.3; range=41–88	
Sex: male	40	53 %
Marital status		
Married/partnership	55	72 %
Not in partnership	21	28 %
Children: yes	64	84 %
Educational level		
Primary	03	04 %
Secondary	43	57 %
Tertiary	25	33 %
Other	05	07 %
Employment status		
Retired	44	58 %
Employed	20	26 %
Home management	12	16 %
Unemployed/others	15	20 %
Time since surgery (years)	Median 5.1; range=1.3–9.2	
Location of tumor		
Colon	58	76 %
Rectum	18	24 %
Stoma: yes	13	17 %
Disease stage		
I	13	17 %
II	31	41 %
III	32	42 %
Additional treatment		
Chemotherapy: yes	24	32 %
Radiotherapy: yes	10	13 %

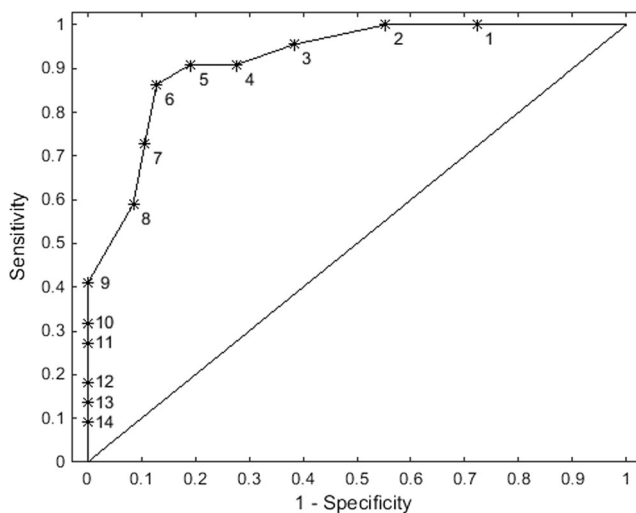


Fig. 1 Receiving operating characteristics curve of Cancer Worry Scale (CWS) scores against the FCRI-SF ≥ 16 . Labeled points correspond to the CWS scores as follows: 1: 8 versus 9; 2: 9 versus 10; 3: 10 versus 11; 4: 11 versus 12; 5: 12 versus 13; 6: 13 versus 14; 7: 14 versus 15; 8: 15 versus 16; 9: 16 versus 17; 10: 17 versus 18; 11: 18 versus 19; 12: 20 versus 21; 13: 22 versus 23; 14: 23 versus 24

Table 2 Accuracy measures for CWS scores according to FCRI-SF

CWS cut-off Score	Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
8 vs 9	100	28	39	100
9 vs 10	100	45	46	100
10 vs 11	96	61	54	97
11 vs 12	91	72	61	94
12 vs 13	91	81	69	95
13 vs 14	86	87	76	93
14 vs 15	73	89	76	88
15 vs 16	59	92	76	83
16 vs 17	41	100	100	78
17 vs 18	32	100	100	76
18 vs 19	27	100	100	75
20 vs 21	18	100	100	72
22 vs 23	14	100	100	71
23 vs 24	9	100	100	70

NPV negative predictive value, PPV positive predictive value

presence or absence of a FCR diagnosis reflecting a Cohen's kappa of 0.71 (SE 0.09).

Reliability

Prevalence and multidimensional aspects of high FCR

According to the established cut-off point of 14 or higher on the CWS, 29 survivors (38 %) had high levels of FCR. These individuals experienced significantly more psychological distress, functional impairments, and triggers, showed more insight, and sought reassurance more often than the individuals with lower levels of FCR (Table 3).

Relationship between FCR and demographic and medical variables

There were no differences in age ($t(74)=1.58, p=0.12$) or time since surgery ($t(74)=-0.31, p=0.76$) between survivors with high or low levels of FCR. Chi-square tests showed categorical demographic (gender, partnership, children, educational level, employment status) and medical variables (location of tumor, stoma, disease stage, additional treatment) not to be associated with FCR.

Relationship between FCR and distress

Survivors with high levels of FCR experienced significantly more general distress ($t(73)=-5.4, p<0.001$) and cancer-specific distress ($t(26.5)=-3.9, p=0.001$) characterized by post-traumatic stress symptoms including significantly more intrusive ($t(31.3)=-3.8, p=0.001$) and avoidant

Table 3 Means and standard deviations of the psychosocial variables

	Low FCR (<i>n</i> =47) CWS<14		High FCR (<i>n</i> =29) CWS≥14		<i>p</i> value
	Mean	SD	Mean	SD	
EORTC QLQ-C30					
Global health/QoL ^c	77.6	(19.1)	56.7	(26.7)	<i>p</i> <0.001
Physical functioning ^b	81.1	(21.9)	68.5	(30.7)	<i>p</i> =0.052
Role functioning ^c	81.7	(24.1)	59.6	(38.1)	<i>p</i> =0.004
Emotional functioning ^c	93.5	(11.3)	72.4	(23.9)	<i>p</i> <0.001
Cognitive functioning ^b	86.5	(18.9)	68.6	(25.1)	<i>p</i> =0.001
Social functioning ^c	93.7	(12.7)	62.8	(38.7)	<i>p</i> <0.001
EORTC QLQ-CR38					
Body image ^c	91.4	(15.1)	70.4	(32.8)	<i>p</i> <0.001
Sexual functioning	23.0	(22.6)	20.4	(19.8)	<i>p</i> =0.623
Future perspective ^c	88.9	(15.9)	56.8	(27.4)	<i>p</i> <0.001
General distress					
HADS total	5.5	(5.0)	13.8	(6.9)	<i>p</i> <0.001
Cancer-specific distress					
IES total	2.8	(6.3)	15.4	(14.6)	<i>p</i> =0.001
Intrusion	1.9	(3.9)	8.2	(7.9)	<i>p</i> =0.001
Avoidance	0.9	(2.5)	8.0	(7.4)	<i>p</i> <0.001
FCRI					
Triggers	6.3	(5.6)	15.5	(5.6)	<i>p</i> <0.001
Psychological distress	1.9	(2.0)	7.6	(3.5)	<i>p</i> <0.001
Functioning impairments	1.1	(2.1)	6.9	(5.3)	<i>p</i> <0.001
Insight	0.3	(0.7)	2.1	(2.2)	<i>p</i> <0.001
Reassurance	1.1	(2.0)	2.9	(3.1)	<i>p</i> =0.005

^a small difference 5–10 points

^b medium difference 10–20 points

^c large difference >20 points

($t(27.2)=-4.6, p<0.001$) phenomena after the traumatic experience of cancer, than did survivors with low levels of FCR (Table 3).

Relationship between FCR and quality of life

Compared with low levels of FCR, high levels of FCR were associated with a poorer quality of life ($F(1,66)=14.1, p<0.001$) more impaired role functioning ($F(1,66)=8.7, p=0.004$), emotional functioning, ($F(1,66)=24.0, p<0.001$), cognitive functioning ($F(1,66)=11.2, p=0.001$), and social functioning ($F(1,66)=22.9, p<0.001$). Moreover, there were large (>20 points) clinically relevant differences between survivors with a high or low FCR in global quality of life, role functioning, emotional functioning, and social functioning. Survivors with a high FCR had significantly more problems with body image ($F(1,70)=13.7, p<0.001$) and future perspective ($F(1,70)=39.6, p<0.001$) than did survivors with a low FCR (Table 3).

Descriptive analyses FCRI

Triggers Medical examinations, feeling sick or physically unwell, and an appointment with the doctor or other health professional were the most frequently reported triggers for high FCR with 48, 45 and 38 % respectively reporting them “most of the time” or “all the time”.

Psychological distress When survivors with high FCR thought about the possibility of cancer recurrence, they felt helpless or resign and expressed worry, fear, or anxiety with 34 and 31 % respectively reporting them “most of the time” or “all the time”.

Functioning impairments High FCR disrupted the ability to make future plans or set life goals, relationships with partner/family, and general quality of life with 18, 17, and 17 % respectively reporting them “most of the time” or “all the time”.

Insight Most survivors with high FCR did not feel that they worried excessively about the possibility of cancer recurrence

or that other people thought they did with 76 and 86 % respectively reporting this “not at all” or “a little”.

Reassurance Survivors with high FCR sought reassurance by going to the hospital or clinic for an examination or calling their doctor or another health professional with 21 and 21 % respectively reporting them “most of the time” or “all the time”. Few such individuals examined themselves to see if they have any physical signs of cancer with 10.7 % reporting this “most of the time” or “all the time”.

Coping strategies Survivors with high FCR coped with this fear by trying to convince themselves that everything would be fine or think positively, trying to find a solution, and trying to replace this thought with a more pleasant with 39, 36, and 32 % respectively reporting them “most of the time” or “all the time”.

These individuals did not use coping strategies such as praying, meditating or relaxation, trying to distract themselves, or trying not think about it with 75, 61, and 57 % respectively reporting them “never” or “rarely”.

Severity The thought that it is normal to be anxious or worried about the possibility of cancer recurrence and the experience of a lot of other unpleasant thoughts or images such as death, suffering, and consequences for family when thinking about the possibility of cancer recurrence were most frequently reported with 61 and 52 % respectively reporting them “most of the time” or “all the time”.

Discussion

This is one of the few studies to specifically focus on the prevalence and features associated with FCR in CRC survivors. FCR remains a significant problem for some CRC survivors even years after diagnosis, when routine follow-up care has normally ended. This study supported the reliability and criterion validity of the CWS in a sample of CRC survivors. Furthermore, the CWS showed good discriminatory power relative to the FCRI-SF, indicating that it is an appropriate instrument to identify those individuals who experience high FCR. Similar to the validated cut-off score in a sample of breast cancer survivors [23], a cut-off score of 14 or higher was optimal for differentiating a case from a non-case. With this cut-off point, about one third (38 %) of the survivors experienced high levels of FCR a median time of 5 years after surgery. Levels of FCR were not different for men or women, age, or medical characteristics. These findings are partly in line with the recent systematic review of Simard and colleagues [11] which showed moderate evidence (4 studies evidence; 12 studies no evidence) for a relation between FCR and gender and only weak to moderate evidence for a relation

with disease and treatment characteristics. Although a relation between FCR and age is often observed in the literature, there was no significant correlation in this study. A possible explanation could be that there participated both males and females in this study. The systematic review of Simard and colleagues [11] namely revealed that in 18 studies, of which eight included samples of only males, no significant relationship with age was found. It might be the case that there is no association between age and FCR in male cancer survivors, and therewith, the relationship in this mixed sample disappeared.

In accordance with previous studies, the CRC survivors in this study reported a good global quality of life [6]. However, there were large statistically and clinically relevant differences between individuals who reported high or low levels of FCR, with high FCR being associated with a lower general quality of life, lower emotional functioning, role functioning and social functioning, and more problems with body image and future perspective. Furthermore, individuals with high FCR had higher levels of general distress and post-traumatic stress symptoms, such as avoidance and intrusions. This is consistent with the results of studies among cancer patients reporting that intrusive thoughts are more frequently related to future-oriented fears, such as FCR [34–38]. Simard and colleagues [13] revealed that the nature of these intrusive thoughts associated with FCR shares characteristics with worries, negative and uncontrollable thoughts on an issue whose outcome is uncertain but which contains the possibility a negative outcome [39]. More severe FCR tends to resemble obsession, defined as recurrent thoughts and images, experienced as intrusive and inappropriate, causing anxiety and psychological distress [40]. This was also supported by the results of this study since CRC survivors with high FCR reported unpleasant thoughts or images such as death, suffering, or consequences for family when thinking about the possibility of cancer recurrence as one of the most frequently occurring features of FCR. Furthermore, the results showed that high FCR is characterized by reactions to specific triggers, negative thoughts, and feelings accompanied by reassurance behavior. Interestingly, reassurance behavior mainly consisted of contact with one’s medical professional. Body checking occurred less frequently. An explanation for this finding might be that it is more difficult for CRC survivors to check their body for symptoms of recurrence than for breast cancer survivors. CRC survivors might be more focused on their defecation than on their body. Since CRC survivors with high FCR do not experience their fear as excessive or unreasonable (insight) but the focus seems meanwhile to be on dysfunctional thoughts or behaviors, CRC survivors with high FCR may benefit from cognitive behavior therapy [41–44].

The study had some limitations. The low response rate (38 %) and small sample size means that results might not be representative. It is possible that survivors who have been disease-free for a number of years might not want to think

about hospitals and cancer research. Alternatively, it might be the survivors with the most severe problems, with high levels of FCR, or distress who do not participate. Despite the small sample size, statistically and clinically relevant differences were found between individuals with high and low levels of FCR, and descriptive analysis was possible.

Another limitation is the difference between responders and non-responders, which could be indicative of selection bias. However, compared to the Dutch cancer population at the time of this study, age categories, and gender distribution were quite similar, indicating that it was a representative sample [45].

Although reliability and criterion validity of the CWS were established in a population of CRC survivors, not all components of validity were assessed. Future research should address multiple components of validity.

Conclusions

This study emphasizes the need to focus on specific problems rather than general QoL, but these findings should be confirmed with a larger sample using a prospective design. We are currently investigating FCR, distress, and QoL in the first year after the diagnosis of CRC. Future research should aim to develop an evidence-based intervention for CRC survivors with high FCR, and the results of the current study may provide starting points for such an intervention.

Conflict of interest The authors declare that they have no competing interests.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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