Use of a Web-based Risk Appraisal Tool for Assessing Family History and Lifestyle Factors in Primary Care

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BACKGROUND: Primary care clinicians can play an important role in identifying individuals at increased risk of cancer, but often do not obtain detailed information on family history or lifestyle factors from their patients.

OBJECTIVE: We evaluated the feasibility and effectiveness of using a web-based risk appraisal tool in the primary care setting.

DESIGN: Five primary care practices within an academic care network were assigned to the intervention or control group.

PARTICIPANTS: We included 15,495 patients who had a new patient visit or annual exam during an 8-month period in 2010–2011.

INTERVENTION: Intervention patients were asked to complete a web-based risk appraisal tool on a laptop computer immediately before their visit. Information on family history of cancer was sent to their electronic health record (EHR) for clinicians to view; if accepted, it populated coded fields and could trigger clinician reminders about colon and breast cancer screening.

MAIN MEASURES: The main outcome measure was new documentation of a positive family history of cancer in coded EHR fields. Secondary outcomes included clinician reminders about screening and discussion of family history, lifestyle factors, and screening.

KEY RESULTS: Among eligible intervention patients, 2.0 % had new information on family history of cancer entered in the EHR within 30 days after the visit, compared to 0.6 % of eligible control patients (adjusted odds ratio = 4.3, $p = 0.03$). There were no significant differences in the percent of patients who received moderate or high risk reminders for colon or breast cancer screening.

CONCLUSIONS: Use of this tool was associated with increased documentation of family history of cancer in the EHR, although the percentage of patients with new family history information was low in both groups. Further research is needed to determine how risk

appraisal tools can be integrated with workflow and how they affect screening and health behaviors.

KEY WORDS: risk appraisal; family history; cancer; primary care.

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INTRODUCTION

Family history and lifestyle factors represent established risk factors for cancer and other chronic diseases.^{1–4} Identifying individuals at increased risk of cancer can help reduce incidence and mortality.^{1,5,6} Primary care clinicians can play a critical role in this process by asking patients about family history and lifestyle factors, counseling them about risk, and making recommendations for prevention and screening. However, primary care clinicians have limited time during visits and may lack adequate systems for collecting and synthesizing this information.^{7,8} As a result, they often do not obtain detailed information on family history or lifestyle factors, and they may be uncertain about how to use this information.^{9–13}

Health risk appraisals (HRAs) have the potential to assist primary care clinicians with this process, especially if they are integrated with electronic health records (EHRs) and linked to appropriate follow-up care.¹⁴ HRAs can be used to collect information on family history and lifestyle factors in a more efficient manner, summarize risk for multiple conditions, and share this information with patients and clinicians. They also may promote communication between patients and clinicians and stimulate behavior change. To date, however, most HRAs have been implemented in workplace settings, and few studies have evaluated their use in primary care.¹⁴ To our knowledge, no prior studies have evaluated a patient-reported HRA that is linked to an EHR.

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To address this, we adapted an existing tool called *Your Health Snapshot (YHS)*, a brief, web-based risk appraisal designed to estimate risk of cancer, heart disease, diabetes, and stroke in the general population. We integrated this tool with an existing EHR and conducted a trial to examine its feasibility and effectiveness in the primary care setting.

METHODS

Study Design and Participants

We conducted a study within five primary care practices (three intervention, two control) at Partners Healthcare, a large academic care network in Boston, MA (Fig. 1). All of the practices used the Longitudinal Medical Record (LMR), an internally-developed, certified EHR.¹⁵ Intervention practices had to have adequate space in the waiting area for patients to complete *YHS* and administrative staff at the front desk to assist with implementation.

Within the five participating practices, eligible patients had to have a new patient visit or an annual exam between December 13, 2010 and August 19, 2011. They also had to be between 18 and 75 years old, speak English, and have a phone number in the LMR. We excluded patients who had a positive family history of cancer already documented in coded LMR fields before their visit. Eligible patients in the three intervention practices were asked to complete *YHS*, a web-based risk appraisal tool, at their visit. Outcome data were collected from the LMR and from a follow-up phone survey conducted among a subset of intervention and

control patients. The study was approved by the Partners Human Research Committee.

Risk Appraisal Tool

Your Health Snapshot (YHS) is a self-administered, web-based risk appraisal tool that is built on the framework of the risk assessment website, *Your Disease Risk* (www.your-diseaserisk.wustl.edu).^{16,17} The calculations and algorithms used in *Your Disease Risk* are the product of an ongoing group consensus process that assigns relative risk estimates to environmental, dietary, and lifestyle factors based on relevant epidemiologic studies.^{16,18}

YHS is a modified version of *Your Disease Risk* that includes similar questions about lifestyle factors and a brief diet assessment.¹⁹ It is appropriate for an 8th-grade literacy level and takes 10–15 minutes to complete. We expanded *YHS* to include questions about which first-degree and second-degree relatives have been diagnosed with cancer and their approximate age at diagnosis. Based on lifestyle factors and family history, *YHS* provides risk estimates for several cancers (colon cancer, lung cancer, breast cancer for women, and prostate cancer for men), heart disease, diabetes, and stroke. Risk estimates are expressed qualitatively as relative risk categories compared to other individuals of the same age and gender. At the end of *YHS*, a brief summary report is generated with the estimated risk for each condition, as well as tailored recommendations for prevention (Fig. 2).

Figure 1. Recruitment and enrollment in *Your Health Snapshot* study.

Snapshot Results

Figure 2. Screenshot of *Your Health Snapshot* summary report.

Recruitment and Procedures

Eligible patients were identified 4 weeks before their visit using information from the LMR and the scheduling system. Eligible intervention patients were mailed an introductory letter asking them to arrive 30 minutes early for their appointment if they wished to complete *YHS*. Patients who arrived at least 10 minutes early were asked to complete *YHS* on a laptop computer in the waiting area. If the patient wanted to participate, a Research Assistant or one of the front desk staff gave the patient a laptop to complete *YHS*; the patient then completed it independently, without assistance. The first two screens included informed consent.

After completing *YHS*, patients could view the summary report on the screen and print it to bring into their visit. In addition, any patient-entered information on family history of cancer was sent to a special queue linked to the LMR, where the primary care clinician could view it and decide whether to accept it. If accepted, it populated coded fields in the LMR that are used by clinical decision support, which generates reminders for clinicians about colon and breast cancer screening, based on familial risk.

Data Collection and Outcomes

All of the data entered into *YHS* by intervention patients were saved on a firewall-protected server. Data on family history of cancer as well as other demographic and clinical characteristics were obtained from the LMR for both intervention and control patients.

Patients in the intervention group who completed *YHS* were contacted by phone between 1 and 4 weeks after their visit to complete a brief follow-up survey using interactive voice response (IVR) technology. The survey included questions about discussion of family history, lifestyle factors, and screening with the clinician during the visit, as well as perceived cancer risk and satisfaction with the visit. A random sample of 20 % of eligible control patients also was contacted after their visit to complete the same survey.

The main outcome measure was the proportion of patients with new documentation of a positive family history of cancer (i.e., new information on any relative with a history of cancer) entered by the clinician into coded LMR fields within 30 days after the visit. We also examined the proportion of patients who had new clinician reminders about colon or breast cancer screening in the LMR within 30 days after the visit indicating moderate or high risk, and the proportion of patients who reported discussing family history, lifestyle factors, and screening with their clinician during the visit.

Statistical Analysis

Descriptive statistics were computed for all eligible intervention and control patients, as well as for intervention

patients who completed *YHS*. Frequencies for the outcome variables were compared for intervention and control patients. Logistic regression models with generalized estimating equations were used to compute odds ratios (ORs) and 95 % confidence intervals (CIs) for intervention compared to control patients, accounting for clustering by clinician. We adjusted for potential confounders that were selected a priori.

For the analyses of new documentation of a positive family history of cancer and new screening reminders, we first compared all eligible intervention patients to all eligible control patients. We also conducted analyses comparing intervention patients who completed *YHS* to a sample of control patients who were selected using a propensity score to identify patients who would have been most likely to complete *YHS*. We fit a logistic regression model among eligible intervention patients, where the dependent variable was completion of *YHS* and the independent variables were demographic and clinical characteristics. We used the estimated coefficients from this model to compute each control patient's predicted probability of completing *YHS*, and selected the same proportion of control patients as the proportion of intervention patients who had completed *YHS*. For the analyses of discussion of family history and lifestyle factors, we compared all intervention and control patients who completed the follow-up phone survey. The statistical analyses were conducted using SAS version 9.2 (Cary, NC), with $p < 0.05$ as the criterion for statistical significance.

RESULTS

There were a total of 9,647 eligible patients in the intervention practices and 5,848 eligible patients in the control practices; 996 intervention patients (10.3 % of eligible) completed *YHS* (Fig. 1). The most common reason for not completing *YHS* was that patients did not have enough time before their visit (64.6 %); only 1.3 % of patients did not complete it because they did not know how to use the laptop computer. The follow-up survey was completed by 350 intervention patients (46.1 % of those contacted) and 240 control patients (20.2 % of those contacted).

Compared to eligible control patients, eligible intervention patients were older and a greater proportion were female, white, married or living with a partner, and returning patients (Table 1). Intervention patients who completed *YHS* were somewhat older and a greater proportion were married or living with a partner.

Among intervention patients who completed *YHS*, 3.5 % were above average risk for colon cancer, 20.9 % were above average risk for lung cancer, 9.1 % were above average risk for breast cancer (women only), and 43.3 %

were above average risk for prostate cancer (men only) (Table 2). A large proportion of *YHS* completers reported having at least one first- or second-degree relative with cancer (72.9 %); the most common cancers were breast cancer (23.1 %), lung cancer (21.6 %), colon cancer (21.0 %), and prostate cancer (15.0 %).

Eligible intervention patients were more likely than eligible control patients to have new documentation of a positive family history of cancer within 30 days after the visit (2.0 % versus 0.6 %, $p = 0.02$) (Table 3); the adjusted OR was 4.3 (95 % CI: 1.2–15.7, $p = 0.03$). In analyses comparing the 996 *YHS* completers to the sample of 637 control patients who were selected based on the propensity score model, 10.6 % of intervention patients and 0.8 % of control patients had new documentation of family history of cancer within 30 days after the visit (adjusted OR = 15.9, 95 % CI: 3.5–72.1, $p = 0.0003$). Among the 726 *YHS* completers who reported at least one first- or second-degree relative with cancer, 95 of these patients (13.1 %) had new documentation of family history of cancer entered or accepted into the LMR within 30 days after the visit; the other 631 (86.9 %) did not have any new documentation of family history of cancer in the LMR.

The percentages of patients who received a clinician reminder for colon cancer screening indicating moderate or high risk did not differ significantly for intervention compared to control patients (Table 4). Only eight women in the intervention practices (0.1 %) received a clinician reminder for breast cancer screening indicating moderate or high risk within 30 days after the visit, and no patients in the control group received these reminders (Table 4); therefore, odds ratios could not be estimated.

A high percentage of patients in both the intervention and control groups reported discussing family history, lifestyle factors, and screening with their clinician during the visit, and there were no significant differences between the groups (Table 5). A higher percentage of patients in the intervention group compared to the control group reported their perceived risk of colon cancer to be above average (16.6 % versus 10.0 %), but this was not associated with increased discussion of family history or screening (data not shown).

DISCUSSION

We evaluated the feasibility and effectiveness of using a web-based risk appraisal tool in the primary care setting. Use of *YHS* was associated with increased documentation of positive family history of cancer in the LMR, although the absolute percentage of patients who had new documentation of family history of cancer was low in both groups. Use of

Table 1. Characteristics of All Eligible Patients (n = 15,495) and Patients who Completed *Your Health Snapshot* (n = 996)

Characteristics	All eligible control patients (n = 5,848)	All eligible intervention patients (n = 9,647)	Patients who completed YHS (n = 996)	P value ^a
	No. (%)	No. (%)	No. (%)	
Age, mean (SD)	50.2 (13.8)	51.1 (13.3)	54.2 (12.5)	< 0.0001
Sex				< 0.0001
Male	2,762 (47.2)	3,672 (38.1)	367 (36.9)	
Female	3,086 (52.8)	5,975 (61.9)	629 (63.2)	
Race/ethnicity				< 0.0001
White	4,597 (78.6)	8,272 (85.8)	884 (88.8)	
Black or African American	509 (8.7)	517 (5.4)	38 (3.8)	
Hispanic or Latino	150 (2.6)	149 (1.5)	14 (1.4)	
Asian	241 (4.1)	327 (3.4)	24 (2.4)	
Other or missing	351 (6.0)	382 (4.0)	36 (3.6)	
Marital status				< 0.0001
Married or living with partner	3,712 (63.5)	6,492 (67.3)	728 (73.1)	
Single, divorced/separated, widowed, or unknown	2,136 (36.5)	3,155 (32.7)	268 (26.9)	
Primary insurance				0.003
Private	5,036 (86.1)	8,300 (86.0)	835 (83.8)	
Medicare	687 (11.8)	1,183 (12.3)	151 (15.2)	
Medicaid	53 (0.9)	40 (0.4)	3 (0.3)	
No insurance, self-pay, or unknown	72 (1.2)	124 (1.3)	7 (0.7)	
Body mass index, mean (SD)	27.7 (5.9)	27.2 (5.8)	27.1 (5.5)	0.0001
Smoking status				< 0.0001
Never	1,620 (27.7)	2,031 (21.1)	220 (22.1)	
Past	716 (12.2)	879 (9.1)	96 (9.6)	
Current	253 (4.3)	464 (4.8)	50 (5.0)	
Missing	3,259 (55.7)	6,273 (65.0)	630 (63.3)	
Type of visit				< 0.0001
New patient	901 (15.4)	630 (6.5)	55 (5.5)	
Returning patient	4,947 (84.6)	9,017 (93.5)	941 (94.5)	
Personal history of cancer	402 (6.9)	653 (6.8)	75 (7.5)	0.80
Personal history of cardiovascular disease	218 (3.7)	380 (3.9)	43 (4.3)	0.51
Personal history of diabetes	157 (2.7)	220 (2.3)	16 (1.6)	0.11

^aP value from *t* tests for continuous variables and chi square tests for categorical variables, comparing all eligible intervention and all eligible control patients

YHS was not associated with increases in moderate or high risk screening reminders to clinicians or discussion of family history, lifestyle factors, or screening.

The Agency for Healthcare Research and Quality (AHRQ) recommends that primary care clinicians collect a detailed family history of cancer from their patients.²⁰ However, primary care clinicians often do not routinely obtain family history information^{9–13} or discuss health behaviors and prevention with patients.^{8,21,22} Risk appraisal tools that assist primary care clinicians with collecting and

interpreting information about family history and lifestyle factors could potentially have an important impact on quality of care.

Few prior studies have evaluated computerized risk appraisal tools for use in the primary care setting. Family HealthwareTM is a self-administered, web-based questionnaire that assesses familial risk for six diseases (colon, breast, and ovarian cancer as well as coronary heart disease, diabetes, stroke) and provides a “prevention plan” with personalized recommendations for lifestyle changes and

Table 2. Estimated Risk Level for Patients in Intervention Practices who Completed *Your Health Snapshot* (n 996)

Condition	Risk category				Not estimated ^a	
	Below average No. (%)	Average No. (%)	Above average No. (%)	Not estimated ^a No. (%)		
Colon cancer	771 (77.4)	183 (18.4)	35 (3.5)	7 (0.7)		
Lung cancer	673 (67.6)	113 (11.3)	208 (20.9)	2 (0.2)		
Breast cancer (women only, n = 629)	353 (56.1)	180 (28.6)	57 (9.1)	39 (6.2)		
Prostate cancer (men only, n = 367)	28 (7.6)	165 (45.0)	159 (43.3)	15 (4.1)		
Condition	Much below average No. (%)	Below average No. (%)	Average No. (%)	Above average No. (%)	Much above average No. (%)	Not estimated ^a No. (%)
Coronary heart disease	737 (74.0)	94 (9.4)	51 (5.1)	62 (6.2)	5 (0.5)	47 (4.7)
Stroke	691 (69.4)	106 (10.6)	66 (6.6)	102 (10.2)	15 (1.5)	16 (1.6)
Diabetes	639 (64.2)	104 (10.4)	63 (6.3)	130 (13.1)	0 (0.0)	60 (6.0)

^aIf a patient reported a personal history of a condition, risk of that condition was not estimated

Table 3. New Coded Data on Positive Family History of Cancer Entered Within 30 Days After Visit

New coded data on family history of cancer	
All eligible patients in intervention group (n=9,647) compared to all eligible patients in control group (n=5,848)	
Intervention, No. (%)	193 (2.0)
Control, No. (%)	34 (0.6)
Unadjusted OR (95 % CI)	3.3 (1.2–9.1)
P value	0.02
Adjusted OR (95 % CI) ^a	4.3 (1.2–15.7)
P value ^a	0.03
Patients who completed YHS in intervention group (n=996) compared to propensity score sample in control group (n=637)^b	
Intervention, No. (%)	106 (10.6)
Control, No. (%)	5 (0.8)
Unadjusted OR (95 % CI)	29.0 (7.2–117.5)
P value	< 0.0001
Adjusted OR (95 % CI) ^a	15.9 (3.5–72.1)
P value ^a	0.0003

^aAdjusted for age, sex, race/ethnicity, insurance, type of visit, study site, and personal history of cancer

^bControl group sample selected using a propensity score model to estimate predicted probability of completing YHS

screening.¹³ A study that used this tool in primary care practices found that a large percentage of patients had a strong or moderate familial risk for at least one of these conditions,²³ which is consistent with our findings, and messages that were tailored to an individual's familial risk

Table 4. New Moderate or High Risk Reminders About Colon and Breast Cancer Screening Within 30 days After Visit

	Moderate/high risk reminders about colon cancer screening	Moderate/high risk reminders about breast cancer screening (females only)
All eligible patients in intervention group (n = 9,647) compared to all eligible in control group (n = 5,848)		
Intervention, No. (%)	101 (1.1)	8 (0.1)
Control, No. (%)	71 (1.2)	0 (0.0)
Unadjusted OR (95 % CI)	0.9 (0.6–1.5)	—
P value ^a	0.75	0.06
Adjusted OR (95 % CI) ^b	1.0 (0.7–1.4)	—
P value ^b	0.84	—
Patients who completed YHS in intervention group (n=996) compared to propensity score sample in control group (n=637)^c		
Intervention, No. (%)	14 (1.4)	3 (0.5)
Control, No. (%)	19 (3.0)	0 (0.0)
Unadjusted OR (95 % CI)	0.5 (0.2–0.9)	—
P value ^a	0.03	0.55
Adjusted OR (95 % CI) ^d	0.4 (0.2–0.9)	—
P value ^d	0.03	—

^aP value for breast cancer screening reminders from Fisher's exact test

^bModels for colon cancer screening reminders adjusted for age, sex, race/ethnicity, insurance, type of visit, study site, and personal history of cancer

^cControl group sample selected using a propensity score model to estimate predicted probability of completing YHS

^dModels for colon cancer screening reminders adjusted for age, sex, and personal history of cancer

were associated with some lifestyle changes.²⁴ However, because Family HealthwareTM was not integrated with an EHR, it is unclear whether the family history information and prevention plan reached primary care clinicians and affected their recommendations; documentation of family history of cancer and clinician reminders about screening were not examined as outcomes. In addition, lifestyle factors are not included in the Family HealthwareTM risk algorithms.

GRAIDS (Genetic Risk Assessment on the Internet with Decision Support) is another computerized decision support tool for assessing family history.²⁵ In a randomized controlled trial, use of GRAIDS was associated with a significant increase in appropriate referrals to genetic clinics and with an improvement in practitioners' confidence in managing familial cancer.²⁶ However, GRAIDS did not assess lifestyle factors, nor was it integrated with an EHR; in addition, the study only examined the proportion of referrals that were consistent with guidelines and did not examine overall documentation of family history of cancer or screening. Other computerized tools for collecting family history have similar limitations.^{27–31}

To our knowledge, ours is the first study to evaluate use of a web-based risk appraisal tool in primary care that incorporates both family history and lifestyle factors and is integrated with an EHR and clinical decision support. The YHS tool is brief and user-friendly, and the summary report contains both estimated risk and tailored recommendations for lifestyle changes. Although a large number of patients in this study reported a family history of cancer on YHS, most of the patient-entered family history information was never accepted into the LMR; this could be due to issues with workflow or with the user interface. Clinicians also may have entered new information on family history of cancer elsewhere in the record (e.g., in a note) rather than in the coded family history fields; this information was not considered to be new documentation of family history of cancer, because it would not be available for clinical decision support.

Furthermore, only a small number of patients received clinician reminders for colon or breast cancer screening in the LMR that indicated moderate or high risk. One reason for this is that much of the patient-entered family history information was not accepted into coded LMR fields, and thus could not be utilized by the clinical decision support that generates the screening reminders. Another issue is that the reminders are not generated until clinicians return to the initial summary screen within the LMR; therefore, the reminder may not be generated until the patient comes back for a subsequent visit. Finally, the existing clinical decision support within the LMR only considers family history and does not incorporate other lifestyle factors which affect risk.

Our implementation of the YHS tool has several limitations. As previously mentioned, although the tool assesses both family history and lifestyle factors, only the information on family history of cancer was integrated with the LMR; therefore, much of the patient-entered data was

Table 5. Discussion of Family History, Lifestyle Factors, and Screening With Clinician During Visit and Perceived Cancer Risk and Satisfaction With Visit

	Intervention (n = 350)	Control (n = 240)		
	No. (%)	No. (%)	Adjusted OR (95 % CI) ^a	P value
Discussion of family history	248 (70.9)	177 (73.8)	0.9 (0.6–1.4)	0.63
Discussion of weight	248 (70.9)	184 (76.7)	0.8 (0.5–1.2)	0.27
Discussion of diet or nutrition	230 (65.7)	163 (67.9)	1.0 (0.7–1.4)	0.86
Discussion of physical activity or exercise	293 (83.7)	210 (87.5)	0.7 (0.4–1.1)	0.12
Discussion of smoking	178 (50.9)	127 (52.9)	1.0 (0.7–1.6)	0.90
Discussion of colon cancer screening (over 50 only)	195 (75.0)	109 (71.7)	1.2 (0.6–2.5)	0.62
Above average perceived risk of colon cancer	58 (16.6)	24 (10.0)	1.7 (1.1–2.6)	0.02
Discussion of breast cancer screening (women over 40 only)	196 (90.7)	102 (88.7)	1.3 (0.7–2.4)	0.47
Above average perceived risk of breast cancer (women only)	44 (18.0)	19 (14.0)	1.2 (0.7–2.1)	0.57
Very satisfied with visit	248 (70.9)	156 (65.0)	1.1 (0.7–1.8)	0.56

^aAdjusted for age, sex, race/ethnicity, insurance, type of visit, study site, and personal history of cancer

not readily available to clinicians. Another limitation was that the tool only could be completed on a laptop computer in the waiting area of the primary care practices, and many patients did not have sufficient time to complete it; it would be useful to offer it through other mechanisms, such as IVR or personal health records, which would make it possible for patients to access it from home or elsewhere. Finally, the *YHS* tool was not directly linked to any follow-up care.

Our evaluation also had limitations. First, a small number of practices were selected and the group assignment was not randomized; this led to some differences between eligible patients in the intervention and control groups, although we adjusted for these in our multivariate models and the results were similar, suggesting that the observed associations were not explained by these factors. Another limitation is that only a small percentage of eligible patients in the intervention group completed *YHS*. We addressed this by comparing all eligible patients in the intervention group to all eligible patients in the control group, and then by comparing *YHS* completers to a sample of control patients who would have been most likely to complete the tool. This study also was conducted at a small number of primary care practices at a single institution with an existing EHR, which could affect its generalizability. Finally, a larger study population and a longer follow-up period are needed to examine the effects of the *YHS* tool on clinician screening reminders and, more importantly, actual screening and health behaviors among patients; the intervention would need to lead to differences in these outcomes in order to have a meaningful impact on cancer mortality. Despite these limitations, however, the results of this preliminary study should inform future research using risk appraisal tools in primary care.

In conclusion, it is feasible to use a brief, web-based risk appraisal tool to assess family history and lifestyle factors in the primary care setting. Use of this tool was associated with increased documentation of family history of cancer in the EHR, although the percentage of patients with new family history information was still low. Further studies,

especially large randomized controlled trials with longer follow-up periods, are needed to determine how risk appraisal tools using patient-entered data can be integrated with workflow, and to examine their effects on screening and health behaviors. In addition, future research should focus on new ways for clinical decision support to utilize information on family history and other risk factors in the EHR.

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