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ILLNESS BELIEFS AND PERCEPTION OF PROGNOSTIC RISK IN PATIENTS RECENTLY DIAGNOSED WITH MULTIPLE SCLEROSIS

Abstract

Objective: Patients' beliefs about their illness may affect their expectations about future disease progression. The aim of this study was to investigate the relation between illness beliefs and perception of *prognostic* risk in patients recently diagnosed with multiple sclerosis (MS). **Methods:** Hundred and one patients were included. Illness beliefs were measured using the Illness Perception Questionnaire (IPQ). Perceived risk and seriousness were assessed for the 2-year, 10-year and lifetime prognosis of wheelchair dependence. Clinical disability status was assessed by a physician. **Results:** Patients who reported a higher intensity of disease-attributed symptoms (IPQ illness identity) had higher perception of the 2-year (regression coefficient $B = 0.58$, $p = 0.02$) and 10-year risk of wheelchair dependence ($B = 0.76$, $p = 0.009$), after adjustment for clinical disability status. IPQ coherence was significantly associated with perceived seriousness: patients who believed they had a clearer understanding of their illness, considered future wheelchair dependence less serious ($B = -1.10$, $p = 0.03$). None of the other IPQ scales were significantly related to perceived risk and seriousness of wheelchair dependence. **Conclusions:** Perceived symptoms were significantly related with short- and medium-term expectations of disease progression. Implications for the clinical care of patients and future research are discussed.

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Introduction

In recent years, there is increasing interest in the influence of illness beliefs on perception of risk.^[1-7] Beliefs about illness – or illness representations – comprise multiple dimensions including illness identity (intensity of disease-attributed symptoms), timeline (duration and variability of the disease course), consequence, cause, controllability (prevention or cure) and coherence (understanding of the disease).^[8-10] Illness representations have been found to underlie perception of risks of various disorders, such as breast and ovarian cancer and cardiovascular disease.^[3-7,11] For example, healthy individuals were found to use established risk factors (causes) in estimating their risk of heart disease.^[11] Women who reported a family history (causes) or a previous history of benign breast problems (illness identity) more often overestimated their risk of breast cancer.^[3-5]

Research on the relationship between illness representations and perception of risk has primarily focused on the risk of (future) disease. One may argue that illness representations also relate to perception of prognostic risk in persons who already have a (chronic) disease, because both disease risk and prognostic risk deal with uncertain and unfavorable future health outcomes. Yet, it is also expected that several dimensions of illness representations may have a different role in perceived risk of prognosis. First, the presence of risk factors or causes were interpreted as indicators of disease risk,^[3-5,11] but these may not be relevant with regard to prognostic risk. Instead, the presence of disease-attributed symptoms may be perceived as indicative of future disease progression and associated with higher perception of prognostic risk. Second, beliefs about the controllability and the duration of disease, which are dimensions that relate to prognosis, may be of greater influence. For example, patients who believe that they can control the progression of their disease, e.g. by diet or lifestyle changes, may have lower perception of prognostic risk.^[12] The relationship between illness representations and perception of prognostic risk is yet unknown.

The aim of the present study was to examine the relationship between illness beliefs and perceived prognostic risk in patients recently diagnosed with multiple sclerosis (MS). MS is a chronic neurological disease which generally affects young adults between 20 and 40 years of age.^[13] The disease often has disabling consequences such as wheelchair dependence and cognitive decline. The course of disease is highly variable in symptoms, poorly controllable by medication, and unpredictable.^[14] In the absence of clear prognostic information, the role of illness beliefs may be particularly important in determining perception of prognostic risk of patients. If so, intervening on illness beliefs may be a promising strategy to alter apparent unrealistic perceptions of risk.

In this study, we focused on the risk of wheelchair dependence, which is a serious consequence of MS and known to all patients as a possible outcome of their disease. The lifetime risk of wheelchair dependence for MS patients is estimated to be 70-80%.^[15] We have previously demonstrated that patients overestimated their 2-year and 10-year risk of wheelchair dependence and underestimated their lifetime risk.^[16] They considered wheelchair dependence a serious consequence of their disease, irrespective when it would happen.^[16] In the present paper, we studied the association of illness representations with perceived risk and seriousness of wheelchair dependence for these different prognoses, adjusting for differences in clinical disability status.

Method

Participants and procedures

Patients were recruited through the Departments of Neurology of the Erasmus MC (Rotterdam), three hospitals within the region of this academic hospital, and the VU Medical Center (Amsterdam) in the period of March 1999 – December 2000. Patients were diagnosed as having MS within two years before study entry, were between 18 and 55 years old, and had signed informed consent. Diagnoses were verified by senior neurologists from the academic hospitals. Patients with serious comorbidity or with insufficient understanding of the Dutch language were excluded. Of the 120 patients who met the study criteria, 101 agreed to participate in the study. Mean age of the patients was 37.5 years (SD 9.5) and 70% were women. The mean time since diagnosis was only 7.8 months (SD 6.5), and the mean time since first symptoms 3.7 years (SD 4.6).

Patients underwent a neurological examination to determine their disability status. These examinations were done by physicians following a standardized research protocol. Disability status was rated on the Expanded Disability Status Scale (EDSS),^[17] a scale that ranges from 0.0 (no neurological symptoms) to 10.0 (death due to MS). The inability to walk beyond five meters equals a score of 7.0. Scores from 0.0 to 2.5 indicate no to minimal disability and scores from 3.0 and higher indicate moderate to severe disability.^[17] In our study population, EDSS ranged from 0.0 to 7.0. Eighteen percent of the patients experienced problems in walking as indicated by an EDSS score of 4.0 or higher. The study protocol was approved by the medical ethical committees of the participating hospitals.

Psychological instruments

Perception of the risk and seriousness of becoming wheelchair-dependent was assessed for the short- (2-year), medium- (10-year) and long-term (lifetime)

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prognosis. The risk of wheelchair dependence was defined as the inability to walk beyond five meters. Patients were asked to what extent they thought they would become wheelchair-dependent for distances over five meters within these periods. Perception of risk was given by marking a 100mm visual analogue scale (VAS) which ends were anchored at 'Definitely not' (0) and 'Definitely' (100). Next, patients were asked for each period how serious they thought it would be to be wheelchair-dependent by that time. Perceived seriousness was assessed on a VAS from 'Not serious at all' (0) and 'The most serious thing I can imagine' (100). In an at-home interview, patients were asked to elucidate the VAS scores of perceived risk and seriousness.

Illness beliefs were assessed using the Illness Perception Questionnaire (IPQ).^[10,18] The original IPQ consists of five scales: illness identity, cause, time-line (chronic), consequence and control (personal and treatment). The coherence and timeline (cyclical) scales were added from the revised version (IPQ-R).^[18] Answers were rated on a five-point scale ranging from 'Strongly agree' to 'Strongly disagree' (scored 5 to 1), except for the illness identity scale which was rated using a four-point scale. An overview of the scales, typical questions, ranges and reliability of the scales is presented in Table 1. Internal consistency of the scales was evaluated using Coefficient α , which for this research purpose was considered adequate when higher than 0.70.^[19] Several scales needed adaptations before their application in this study. First, the illness identity scale comprises intensity ratings of symptoms that patients experience and attribute to their disease. As recommended,^[10,18] this scale was adapted for use in an MS population. The scale consists of 23 symptoms: twelve symptoms were taken from the IPQ list (excluding breathlessness) and eleven were added (concentration problems, coordination problems, muscular pain, numbness of limbs, loss of balance, feelings of depression, blurred vision, diplopia, bladder symptoms, bowel symptoms and spasticity). Answers were scored on 4-point scales: all of the time = 4, frequently = 3, occasionally = 2, and never = 1. These scores sum into a total score ranging from 23 to 92. Coefficient α of the new symptom scale was 0.87. Second, the cause scale originally consisting of 19 distinct causes of disease, was compressed using principal component analysis (PCA) with Varimax rotation. Five causal factors with eigenvalues exceeding 1 were found, and labeled based on their contents as psychological, external, lifestyle, chance and germ or virus (see Table 1). Finally, Coefficient α of four IPQ scales was lower than 0.70. The timeline (cyclical) scale ($\alpha = 0.32$) was shortened by removing three items, resulting in a sufficient reliability ($\alpha = 0.72$) with only two items left. Because these items ('My symptoms come and go in cycles' and 'I go through cycles in which my illness get

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Table 1 Overview of the Illness Perception Questionnaire (IPQ) scales

Scale	Examples	Number of items	Possible range	α^*
Identity	To what extent do you experience the following symptoms due to your disease? (see Methods)	23	23-92	0.87
Timeline acute/chronic	My illness will last a long time. My illness is permanent rather than temporary.	3	3-15	0.82
Timeline cyclical	I go through cycles in which my illness gets better and worse.	5	5-25	0.32†
Treatment control	There is very little that can be done to improve my illness (r). My treatment will be effective in curing my illness.	3	3-15	0.66
Personal control	There is a lot, which I can do to control my symptoms. What I do can determine whether my illness gets better or worse. Recovery from my illness is largely dependent on chance or fate (r).	3	3-15	-0.02‡
Consequences	My illness is easy to live with (r). My illness is a serious condition.	7	7-35	0.72
Coherence	The symptoms of my condition are puzzling to me (r). I have a clear picture or understanding of my condition.	5	5-25	0.82
Causal attributions				
Psychological	Personality, my behavior, family problems or worries, stress or worry, mental attitude, emotional state, overwork.	7	7-35	0.89
External	Accident or injury, poor medical care in the past, environmental pollution.	3	3-15	0.72
Lifestyle	Alcohol, diet or eating habits, altered immunity, smoking.	4	4-20	0.83
Chance	Chance or bad luck, aging and heredity.	3	3-15	0.48
Germ or virus	Germ or virus	1	1-5	-

(r) Items that are reverse scored. * Coefficient α indicates internal consistency reliability in the present study. † Coefficient α was 0.72 after item reduction (see Methods). ‡ Checked for errors in recoding.

better and worse') are most relevant in MS, we decided to use the two-item scale in further analyses. The reliability of the personal control scale and chance attributions did not improve from item reduction, and were for that reason excluded from the regression analyses together with the germ attribution scale. The treatment control scale was included in the analyses in its original form, because its reliability was considered borderline ($\alpha = 0.66$).^[19]

Statistical analysis

Pearson correlation coefficients were calculated to investigate the association between illness representations (IPQ scales), disability status (EDSS), perceptions of risk and seriousness. The relationship between illness representations and

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perceived risk and seriousness of wheelchair dependence were studied adjusting for clinical disability status using SAS Proc Mixed Repeated Measurements. This MANOVA-like procedure was chosen because of the substantial intercorrelations of perceived risk and seriousness between the three periods (2 years, 10 years and lifetime).^[16] The following strategy of analysis was adopted. Prognosis was recoded into 0, 1 and 2 representing 2-year, 10-year and lifetime risks. A full model was tested including prognosis (2-year, 10-year and lifetime risk), main effects (disability status and IPQ scales), covariates (time since diagnosis, time since first symptoms, age and sex) and first-order interaction effects of the main effects with prognosis. To simplify the model, this saturated model was reduced by eliminating non-significant covariates and interaction effects. Elimination was based on the significance of the difference in $-2 \log$ likelihood goodness of fit between the reduced and the saturated model. If the p-value was greater than 0.05 (χ^2 -test), the parsimonious model was considered not significantly different from the saturated model, and used for further simplification. Regression coefficients (B) of the final model were estimated using the restricted maximum likelihood procedure (REML).

Results

Correlations between disability status and illness representations

Table 2 shows that patients with more physical limitations (EDSS) reported a higher intensity of symptoms as measured by the IPQ illness identity scale ($r = 0.53$, $p < 0.001$). The most prevalent symptom was fatigue, which was experienced 'frequently' or 'all of the time' by 61% of the patients. Other common symptoms were sensory problems (e.g. numbness of limbs; 44%), loss of strength (26%), loss of balance (25%), stiff joints (23%) and concentration problems (21%). As expected, the intensity of these symptoms was significantly higher among patients with higher physician-assessed disability status ($EDSS \geq 3.0$; $p < 0.05$), except for fatigue ($p = 0.90$). Patients primarily attributed the cause of their disease to four factors: chance or bad luck (46% of the patients agreed or strongly agreed), stress or worry (45%), germ or virus (44%) and altered immunity (43%). The scales of the IPQ were interrelated (Table 2): each scale except the cyclical timeline scale, was significantly correlated to at least three other scales.

Illness beliefs and perceived risk of wheelchair dependence

Table 3 shows the relation between illness representations and perception of risk adjusting for physician-assessed disability status. Patients with more physical limitations had a higher perception of risk ($B = 3.61$, $p = 0.003$). This relationship was found for the 2-year, 10-year and lifetime prognosis, because the interaction

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Table 2 Means of IPQ scales, intercorrelations and correlations with disability status

Mean (SD)	Illness beliefs (IPQ)									
	1	2	3	4	5	6	7	8	9	
Disability status (EDSS)	0.53***	0.04	-0.07	-0.04	0.29**	-0.17	0.09	0.22*	0.25*	
Illness beliefs (IPQ)										
1. Illness identity	39.5 (8.8)		0.12	0.14	-0.09	0.48***	-0.23*	0.29**	0.20*	0.25*
2. Chronic timeline	12.7 (2.1)			0.24*	-0.43***	0.23*	0.12	0.06	-0.22*	-0.07
3. Cyclical timeline	7.0 (1.8)				0.02	0.13	-0.16	0.09	-0.15	0.08
4. Treatment control	7.1 (2.1)					-0.27**	-0.27**	0.02	0.11	0.05
5. Consequences	22.7 (4.6)						-0.12	0.19	0.07	0.19
6. Coherence	9.2 (3.9)							-0.21*	-0.20*	-0.24*
7. Psychological cause	8.6 (6.2)								0.46***	0.58***
8. External cause	2.9 (2.5)									0.60***
9. Lifestyle cause	3.7 (2.9)									

Values are Pearson correlations: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

effect of disability status and prognosis was not significant. IPQ illness identity was significantly related to perception of risk: patients who reported a higher intensity of symptoms had a higher perception of the 2-year risk of wheelchair dependence ($B = 0.58$, $p = 0.02$) and 10-year risk ($B = 0.76$, $p = 0.009$). In addition, patients who believed they had a better understanding of their disease, as indicated by higher scores of IPQ coherence, tended to have higher perception of risk ($B = 0.80$, $p = 0.07$). None of the other IPQ scales were significantly related to perception of risk.

Since IPQ illness identity was strongly correlated to clinical disability status as rated on the EDSS ($r = 0.53$, $p = 0.0001$; Table 1), we explored whether there were interaction effects between perceived symptoms and EDSS in explaining perceived risk. Therefore, we compared the effect of IPQ illness identity on risk perception between patients with high ($EDSS \geq 3.0$) and low disability ($EDSS < 3.0$, Figure 1). The relationship between IPQ illness identity and perception of risk was stronger in the high disability group compared to the low disability group. Interaction effects between perceived symptoms and disability group were significant for each prognosis ($p < 0.05$).

Illness beliefs and perceived seriousness of wheelchair dependence

Patients with more physical limitations, as indicated by a higher EDSS score, considered wheelchair dependence to be less serious ($B = -4.47$, $p = 0.002$; Table 4). Of the illness beliefs, only coherence was a significant predictor of perceived seriousness: patients who had a more coherent understanding of their illness thought wheelchair dependence to be less serious ($B = -1.10$, $p = 0.03$).

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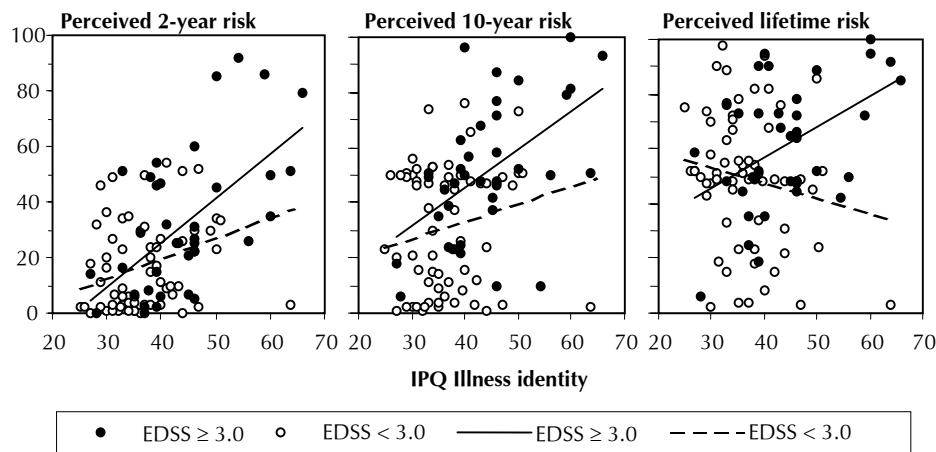


Figure 1 Relationship between IPQ illness identity and perception of risk in high and low disability groups

Dots are crude data. Lines represent linear trends of predicted values of perceived risk obtained by linear regression analyses with additional adjustment for residual confounding of EDSS within the disability groups.

Table 3 Linear model of perceived risk of wheelchair dependence on illness beliefs and disability status

	B [95% CI]	p
Disability status (EDSS)	3.61 [1.28, 5.94]	0.003
Illness beliefs:		
Illness identity ^a		
2-year	0.58 [0.08, 1.09]	0.02
10-year	0.76 [0.19, 1.33]	0.009
lifetime	-0.02 [-0.62, 0.59]*	0.96
Chronic timeline	0.58 [-1.15, 2.31]	0.51
Cyclical timeline	-0.25 [-2.15, 1.65]	0.79
Treatment control	-1.13 [-2.87, 0.60]	0.20
Consequences	0.54 [-0.26, 1.34]	0.19
Coherence	0.80 [-0.05, 1.66]	0.07
Psychological cause	-0.23 [-0.88, 0.42]	0.49
External cause	0.11 [-1.26, 1.48]	0.88
Lifestyle cause	0.91 [-0.56, 2.39]	0.22

Non-significant interaction terms and covariates were removed from the analyses (see Methods). ^a The B coefficient of IPQ illness identity was different for each prognosis. Note that the p-values of IPQ illness identity indicate whether these interaction effects differed from zero. * The B coefficient of IPQ illness identity for the perceived lifetime risk was significantly higher than the B coefficient for the perceived 2-year risk (reference, p < 0.05).

Table 4 Linear model of perceived seriousness of wheelchair dependence on illness beliefs and disability status

	B [95% CI]	p
Disability status (EDSS)	-4.47 [-7.24, -1.70]	0.002
Illness beliefs:		
Illness identity	-0.05 [-0.60, 0.51]	0.87
Chronic timeline	-1.75 [-3.81, 0.30]	0.09
Cyclical timeline	-0.00 [-2.27, 2.26]	1.00
Treatment control	-1.83 [-3.89, 0.24]	0.08
Consequences	0.55 [-0.40, 1.50]	0.26
Coherence	-1.10 [-2.12, -0.09]	0.03
Psychological cause	0.16 [-0.61, 0.93]	0.68
External cause	0.56 [-1.07, 2.20]	0.50
Lifestyle cause	-0.66 [-2.42, 1.10]	0.46

Non-significant interaction terms and covariates were removed from the analyses (see Methods).

This relationship was found for the 2-year, 10-year and lifetime prognosis. None of the other illness representations played a significant role, albeit that there was a tendency that patients who had a stronger belief that their disease was chronic ($B = -1.75$, $p = 0.09$) or controllable by medication ($B = -1.83$, $p = 0.08$) considered wheelchair dependence less serious. None of the interaction effects was statistically significant.

Discussion

In our study of patients recently diagnosed with MS, we investigated whether their beliefs about the disease were associated with their perception of the risk and seriousness of wheelchair dependence. We demonstrated that perceived symptoms, as measured by the IPQ illness identity scale, significantly predicted patients' expectations about future wheelchair dependence. This relationship was found after adjustment for physician-assessed disability status and significant for the 2-year and 10-year prognosis only. Further, patients who believed they had a more coherent understanding of their disease considered the prospects of wheelchair dependence to be less serious. None of the other illness beliefs were significantly related to perceived risk and seriousness of wheelchair dependence.

Before discussing the findings of this study, two methodological issues with regard to the use of the Illness Representation Questionnaire (IPQ) need to be addressed. First, we were unable to replicate the factor structure in the causal attributions as reported in the IPQ-R paper, with the exception of the psychological

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causes (see Table 1).^[18] Factor analysis of causal attributions may be largely determined by the perceived co-occurrence of established causes of disease. This implies that different factor structures may be obtained in different disease populations. Clinical populations may therefore be less suitable for the identification of a general classification of related causes. Second, the personal control scale and, before modification, the cyclical timeline scale were not reliable in our population of MS patients. This may be ascribed to the uncontrollable, unpredictable and variable nature of the disease. Based on our findings, we recommend further refinement of the IPQ-R into a scale in such a way that it can be used in a broad range of diseases without additional modification. A generic illness perception scale with disease-specific modules will facilitate comparison of studies between different centers and different disease groups.

Two major findings can be deducted from this study. First, patients who reported a higher intensity of disease-attributed symptoms had higher perception of the 2- and 10-year risk of wheelchair dependence *after* adjustment for differences in disability status. Our findings and those of others suggest that patients perceive their present symptoms as being indicative of prognosis and extrapolate the presence of symptoms into expectations about future disease progression.^[5,7,20] The fact that perceived symptoms were not related to perceived lifetime risk is likely explained by the unpredictability and variability of MS: also patients with lower EDSS *and* lower IPQ illness identity scores took into account that they might become wheelchair-dependent (see Figure 1). Our exploratory analyses further showed that this relationship between IPQ illness identity and risk perception was stronger in patients with more (physician-assessed) physical limitations. From a clinical point of view these sub-group analyses may be of particular relevance. High symptom perception accompanied with high perception of prognostic risk may be more realistic for patients with severe disability, whereas this may indicate maladaptive coping in those with no to minor disability. Further, low symptom perception and low perception of risk may be more realistic for patients with minimal physical limitations, but may be a sign of avoidant coping behavior in those with moderate to severe disability. Our findings suggest that perception of prognostic risk may be an intermediate factor between illness perceptions and coping.^[22-24] Further, these findings indicate that clinical status is an important factor to include in future studies on illness beliefs.^[21]

The second finding is that patients who believed they had a clearer understanding of their illness, as measured by the IPQ coherence scale, considered wheelchair dependence to be less serious. This relation did not differ for the short-, medium-, and long-term prognosis. This is in line with the hypothesis of Moss-

Morris et al. who suggested that illness coherence may be important in long-term adjustment.^[18] An alternative explanation may be that coherence *reflects* adaptation to the disease. There was support for the latter viewpoint in our interview data. Patients who considered wheelchair dependence less serious indicated that a wheelchair would extend their mobility when they were no longer able to walk (see Chapter 10). They also mentioned that the disease could have consequences that are more serious than wheelchair dependence, or that there are still many opportunities to live a life as normal when being wheelchair-bound (see Chapter 10).

The relation between perceived symptoms and short- and medium-term perception of risk is clinically important because we have previously demonstrated that patients overestimated these short-term risks.^[16] MS is an unpredictable and variable disease with a wide array of possible symptoms. For patients, it may not be easy to determine which symptoms are due to their disease and which are not. It is likely that patients may have an inaccurate perception of their symptoms, which will consequently extrapolate into inappropriate expectations about future disease progression. If so, informing patients which of their symptoms are due to MS may help them to better assess the severity of their disease status and alter eventual unrealistic expectations.

In conclusion, perceived symptoms were associated with perception of short- and medium-term prognostic risk in recently diagnosed MS patients. Contrary to our expectations, however, none of the other IPQ scales were of significant impact. As this is the first study on this topic, it is too early to conclude that illness beliefs do not play a role in perception of prognostic risk. Since illness perceptions could give insight into how patients make judgments about their risks,^[1] they may provide opportunities to alter unrealistic perceptions of risk. Further research on the relationship between illness beliefs and perception of prognostic risk in MS and other chronic diseases is needed but requires refined approaches to assess beliefs.

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