

## Research Article

# The Reliability and Validity of the Japanese Version of Revised Illness Perception Questionnaires for Healthy People (IPQ-RH-J)

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## Abstract

We verified the reliability and validity of the Japanese version of the Revised Illness Perception Questionnaire for Healthy people (IPQ-RH-J) because Japanese scales related illness perceptions for healthy people does not exist. The illness perceptions of two diseases with different characteristic, namely breast cancer (BC) and diabetes (DM), were assessed in 159 females and 109 males in Japan. Using the negative affectivity subscales of the Positive and Negative Affect Scale (NA-PANAS), the discriminant validity was assessed. IPQ-RH-J achieved good scores on all the tests including the construct validity (Comparative Fit of Index (CFI): 0.93 in BC, 0.88 in DM), the discriminant validity (Pearson's correlation ( $r$ ) < 0.2 in BC and DM) and the test-retest reliability (Cronbach's  $\alpha$ : 0.59 to 0.92 in BC, 0.57 to 0.90 in DM). Comparison between the illness perception for breast cancer and that for diabetes revealed the differences in the duration of symptoms, the severity of consequences, feelings of self-control, the emotional representations, and the recognition of the genetic factors. We found that IPQ-RH is universally effective across different cultures and can be used for diseases with gender differences.

Keywords: illness perception, IPQ, healthy people, breast cancer

## Introduction

Leventhal's common-sense model of the illness representations can be used to understand person's illness cognition that is beliefs or perception of illness [1]. The illness representations exhibit dynamic change and has been developed together with a range of resources, including direct experience with disease and medical care; indirect experience through family, friends, and media; and cultural thinking. The theory comprises five core perspectives: 1) identity of the threat, the label representing the idea of the disease based on their experiences and symptoms; 2) cause, the person's ideas about the perceived cause of the illness, namely infection, genetic, stresses, or other sources; 3) timeline, the individual's perceived clinical course and duration of the illness; 4) consequences, the perceived impact of the illness including both physical and psychological effects; and 5) control, the controllability of prevention and treatment.

To understand illness cognition, a scale using the illness representations model (the Illness Perception Questionnaire: IPQ) has been developed [2]. Subsequently, a revised version of the illness cognition scale (the Revised IPQ: IPQ-R) was prepared [3]. These scales determine how specific groups and individu-

als, such as patients and those at risk for certain diseases, perceive their diseases. However, there have been few studies that describe how healthy people think of health and disease and how their thinking is linked to healthy activities. In response to this set of factors, a scale of illness cognition for healthy people (IPQ-R for healthy people: IPQ-RH) was developed [4] to understand illness cognition in society in general.

Many studies have found and support that an array of complex factors related to disease, such as experience, knowledge, and culture, are major deciding factors in the representation of illness (e.g., [5]). When the cause of a disease is genetic, it is often conceptualized as something abstract, uncontrollable, and inexplicable. Such an interpretation is said to be related to "genetic exceptionalism", expressed as a social perspective on genetic information [6]. In the setting of genetic counseling dealing with hereditary diseases, individual differences in the elements based on the illness representation model lead to different recognitions of risk, cost, and benefit with respect to decision making in medical care [7]. Belief and cognition in relation to hereditary diseases are influential factors on genetic risk perception

(e.g., [5]). Therefore, it is important for healthcare professionals in the setting of genetic counseling to understand how a client perceives and believes their illness. To understand clients' illness cognition and prepare appropriate support in genetic counseling, formation and transition of illness cognition must be understood correctly. To that end, it is important to understand the illness cognition of healthy people in general society that can affect the client's personal experience, knowledge, and cultural background.

In this study, we prepared the Japanese version of IPQ-RH (IPQ-RH-J), which was developed as a scale of illness cognition for healthy people in general Japanese society. The translation and cultural adaptation process was based on the report of Wild et al. [8]. We obtained permission to prepare IPQ-RH-J from the author of IPQ-RH and finalized IPQ-RH-J through the following four steps; forward translation, back translation, debriefing, and author's confirmation. The present survey verified the reliability and validity of IPQ-RH-J.

## Methods

### Subjects

We recruited 268 Japanese men and women (aged 20 to 80 years old). The ideal sample size was calculated using the COSMIN (Consensus-Based Standards for the Selection of Health Measurement Instruments) checklist and literatures on the development of IPQ related scales [2-4,9]. Because IPQ-RH was designed for healthy people, subjects with a past/current history of breast cancer or diabetes were asked not to answer questions related to these diseases.

### Questionnaire survey

Informed consent was obtained before answering the questionnaire. To verify reliability and validity, we used three scales: IPQ-RH-J (26 items), the negative affectivity of the Japanese version of Positive and Negative Affect Scale (NA-PANAS) (8 items) [10], and the causal attribution items (16 items, hereinafter described cause). Responses were taken on a five-point Likert scale (from 1 = Strongly disagree to 5 = Strongly agree) for IPQ-RH-J, a six-point Likert scale (from 1 = Not at all to 6 = Extremely) was used for NA-PANAS, and for the cause attribution, we had subjects choose "yes" or "no," that is, whichever they felt was most accurate. Information on subjects' age, sex, and level of education were also gathered.

The survey was conducted on those with consent for this research from December 2018 to February 2019 by web or post mail. We asked the test-retest group to repeat the questionnaire after a three-week interval. The anonymized ID was used so that two individual responses could be linked in the test-retest group and the other subjects were anonymous.

### Statistical analyses

To verify the validity of IPQ-RH-J, we performed confirmatory factor analysis and calculated the fit of the model (GFI: Goodness of Fit Index, AGFI: Adjusted Goodness of Fit Index, CFI: Comparative Fit of Index, and RMSEA: Root Mean Square Error of Approximation) for seven subscales of IPQ-RH-J such as "timeline acute/chronic", "timeline cyclical", "consequences", "personal control", "the treatment control", "illness coher-

ence" and "emotional representations" in the IPQ-RH. GFI and AGFAI show how much the variance-covariance matrix of the estimated model can reproduce the variance-covariance matrix of the actual observation data. CFI is an index of comparative fitness based on how much the model fit improved when compared to the independent model. RMSEA is an index of frugality correction showing the degree of deviation per degree of freedom. In order to verify discriminant validity, we obtained correlation coefficients for the total NA-PANAS scores and the subscale scores. We used the test-retest reliability method. We obtained a total score of the subscale from two answers and calculated Cronbach's alpha and Pearson correlation coefficients. The level of statistical significance was set to  $p < 0.05$ . For statistical analysis, we used SPSS Statistics 26.0.

## Results

### Respondents' characteristics

The demographics of respondents is shown in Table 1. Among the group of 268 respondents, 109 were men and 159 were women, with an average age of 46.4 years old (ranging from 21 to 79 years old).

**Table 1.** The demographic features of respondents

<b>All respondents</b>		
<b>Sex</b>	N	%
Male	109	40.7
Female	159	59.3
Total	268	
<b>Age</b>	years old	
Average	46.4	(21-79)
<b>Final education</b>	N	(%)
Junior high school	8	3.0
Senior high school	64	23.9
College	72	26.9
Undergraduate school	76	28.3
Master's degree	29	10.8
Doctor's degree	19	7.1
<b>Test-retest group</b>		
<b>Sex</b>	N	(%)
Male	20	32.8
Female	41	67.2
Total	61	
<b>Age</b>	years old	
Average	44.5	(22-71)

### Verification of Construct Validity

To calculate the fit of the model, we used SPSS Statistics 26.0. After preparing the path diagram using all 26 items, we added five paths to improve the fit. By adding paths between related items for each subscale, we maximized the fit for both breast cancer and diabetes. The added paths were "this illness will last a short time" to "this illness will pass quickly" (I) and "I expect this illness to last for the rest of one's life" to "this illness is likely to be permanent rather than temporary" (II) in the subscale of the timeline acute/chronic, "the symptom comes and goes in cycles" to "this illness goes through cycles in which gets better or worse" (III) in the timeline cyclical, "this illness is a mystery to me" to

“I don’t understand this illness” (IV) in the illness coherence, and “this illness makes me afraid” to “thinking about having this illness makes me feel anxious” (V) in the emotional representations. Paths I and II were set between the items related to the short or very long duration. Path III was set between the items related to the periodicity of symptoms. Path IV was set between the items related to inability to understand logically and emotionally. Path V was set between the items of negative feelings for the illness. The resulting fit of the model for breast cancer was measured as follows: GFI = 0.878, AGFI = 0.843, CFI = 0.927, and RMSEA = 0.056; for diabetes, these values were GFI = 0.866, AGFI = 0.827, CFI = 0.884, and RMSEA = 0.064.

in Table 2. The correlation coefficients between NA-PANAS and the seven subscales for IPQ-RH-J were less than

**Verification of Discriminant Validity**

The verification results of discriminant validity are shown in Table 2. The correlation coefficients between NA-PANAS and the seven subscales for IPQ-RH-J were less than 0.2 for all items under diabetes and breast cancer, not indicating any correlation. However, there were correlations for the seven subscales of IPQ-RH-J, thus confirming its validity.

**Verification of the Test–Retest Reliabilities**

Table 3 shows the reliability verification result with the test–retest reliability method. Cronbach’s alpha for the seven subscales was 0.590 to 0.919 for breast cancer and 0.573 to 0.898 for diabetes, excluding 0.36 for the cyclical timeline (first time). The Pearson correlation coefficient was 0.339 to 0.794 for breast cancer and 0.387 to 0.760 for diabetes. For all subscales, the result was significant, with  $p < 0.001$ .

**Table 2.** Correlation between subscales of IPQ-RH-J

Scales	1	2	3	4	5	6	7	8	9	10
<b>Breast Cancer (n=268)</b>										
1. Timeline acute/chronic	—									
2. Timeline cyclical	0.299***	—								
3. Consequences	0.405***	0.285***	—							
4. Personal control	0.036	0.270***	0.108	—						
5. Treatment control	0.055	0.139*	0.241***	0.164***	—					
6. Illness coherence	0.177**	0.346***	0.335***	0.278***	0.03	—				
7. Emotional representations	0.213***	0.301***	0.382***	0.182**	0.139*	0.555***	—			
8. Psychological attributions	-0.093	-0.078	-0.116	-0.113	0.02	-0.028	-0.089	—		
9. General risk factors	-0.118	-0.076	-0.041	-0.084	0.042	-0.022	-0.120*	0.594***	—	
10. NA-PANAS	0.076	0.06	0.039	-0.067	-0.109	0.072	0.147*	-0.027	-0.091	—
<b>Diabetes (n=267)</b>										
1. Timeline acute/chronic	—									
2. Timeline cyclical	0.087	—								
3. Consequences	0.495***	0.280***	—							
4. Personal control	0.202**	0.056	0.323***	—						
5. Treatment control	0.142*	0.041	0.114	0.317***	—					
6. Illness coherence	-0.054	0.326***	0.267***	0.054	-0.009	—				
7. Emotional representations	0.174**	0.202**	0.362***	0.101	0.044	0.479***	—			
8. Psychological attributions	-0.026	-0.045	-0.123*	-0.123*	-0.008	-0.052	-0.213***	—		
9. General risk factors	-0.116	-0.071	-0.132*	-0.014	0.045	-0.107	-0.161**	0.500***	—	
10. NA-PANAS	0.031	0.058	-0.002	-0.12	-0.096	0.107	0.177**	-0.132*	-0.150*	—

**Cognition Related to the Cause of illness**

For 16 items on the cause of disease, the subjects answered “yes” or “no” in relation to diabetes and breast cancer (Table 4). Following the previous studies, we divided psychological attributions and general risk factors and calculated the alpha coefficient, finding  $\alpha = 0.707$  and  $\alpha = 0.556$  for diabetes and  $\alpha = 0.755$  and  $\alpha = 0.711$  for breast cancer. The results for breast cancer and diabetes showed no significant difference among the diseases for each cause of psychological attribution, but there was a significant difference in causes “germ or virus”, “immunity”, “alcohol”, “pollution”, “chance or bad luck”, “own behavior”, and “poor diet” for general risk factors.

**Known group validity**

Known-groups validity was assessed by comparing the subscale score among diabetes and breast cancer. The subscale scores of IPQ-RH-J and the scores of the two attributional factors are shown in Table 5. Significant differences were detected in subscales other than the timeline cyclical and the general risk factors.

**Discussion**

In this research, we verified the reliability and validity of IPQ-RH-J using two diseases with different characteristics, breast cancer and diabetes. Since similar results were obtained for both diseases, it was found that the present scale was applicable regardless of the characteristics of the disease. The occurrence risk of breast cancer is significantly higher in women than men. In this survey, in which a similar number of men and women participated, the scale reliability and validity was verified regardless of disease characteristics related to sex. Therefore, this

scale can be used for disease with gender differences. In future, an additional examination with a different group of diseases is necessary for the use of IPQ-RH-J as a general scale for illness cognition.

Petrak et al.[9] examined the fit of IPQ-RH in Croatian and Lebanese women in relation to breast cancer and cervical cancer and showed a fit (CFI) of 0.930 to 0.969 (present research: 0.884 to 0.927) and a Cronbach's alpha ( $\alpha$ ) of 0.66 to 0.82 (present research: 0.57 to 0.92). The Pearson correlation coefficient ( $r$ ) in the test-retest reliability method was 0.40 to 0.93 (present research: 0.34 to 0.77). Petrak's data were consistently high values. In the original paper on IPQ-RH [4], AIDS, skin cancer, and tuberculosis were examined, with results of  $\alpha = 0.60$  to 0.82 and  $r = 0.31$  to 0.78. Our results are comparable to these studies. Some

of our values  $r$  are lower than those found in the data of Petrak et al. [9]. This may be because the diseases that Petrak et al. examined were only cancers that shared characteristics, and all their subjects were women. In addition, there may have been relevant cultural and linguistic differences.

Previously, studies have been conducted of the illness cognition of cancer and diabetes based on illness representations [11,12]. Cancer is usually understood as a serious, threatening disease that can lead to death. For its part, diabetes is considered to be an age-related disease and is not closely linked to death. Although environmental and lifestyle triggers are related to cancer, in addition to genetic risk, diabetes features more factors than cancer does for its occurrence, and it is believed that lifestyle and behavior can reduce risk and control symptoms. The present

**Table 3.** Internal consistency and test-retest reliability of IPQ-RH-J dimension

	Breast cancer (n=61)			Diabetes (n=60)		
	Cronbach's $\alpha$		Pearson's correlation	Cronbach's $\alpha$		Pearson's correlation
	Test	Re-test		Test	Re-test	
Timeline acute/chronic	0.670	0.771	0.570***	0.776	0.870	0.387**
Timeline cyclical	0.590	0.697	0.571***	0.036	0.573	0.430**
Consequences	0.629	0.644	0.755***	0.713	0.650	0.760***
Personal control	0.738	0.814	0.493***	0.773	0.781	0.638***
Treatment control	0.694	0.640	0.339**	0.792	0.663	0.663***
Illness coherence	0.682	0.779	0.794***	0.604	0.819	0.687***
Emotional representations	0.919	0.918	0.771***	0.866	0.898	0.750***

**Table 4.** Perceptions of causal attributions

		Breast cancer (n=268)				Breast cancer (n=268)				Chi-squared test
		Yes		No		Yes		No		
Psychological attributions		$(\alpha=.755)$				$(\alpha=.755)$				
Cause3	Overwork	92	34.3%	176	65.7%	102	38.2%	165	61.8%	n.s.
Cause4	Personality	91	34.0%	177	66.0%	109	40.8%	158	59.2%	n.s.
Cause6	Emotional state	92	34.3%	176	65.7%	84	31.5%	183	68.5%	n.s.
Cause7	Mental attitude	79	29.5%	189	70.5%	73	27.3%	194	72.7%	n.s.
Cause8	Family problems	90	33.6%	178	66.4%	110	41.2%	157	58.8%	n.s.
Cause10	Stress or worry	144	53.7%	124	46.3%	139	52.1%	128	47.9%	n.s.
General risk factors		$(\alpha=.711)$				$(\alpha=.556)$				
Cause1	Heredity	209	78.0%	59	22.0%	199	74.5%	68	25.5%	n.s.
Cause2	Germ or virus	51	19.0%	217	81.0%	20	7.5%	247	92.5%	**
Cause5	Immunity	165	61.6%	103	38.4%	91	34.1%	176	65.9%	***
Cause9	Aging	143	53.4%	125	46.6%	156	58.4%	111	41.6%	n.s.
Cause11	Alcohol	90	33.6%	178	66.4%	213	79.8%	54	20.2%	***
Cause12	Smoking	127	47.4%	141	52.6%	126	47.2%	141	52.8%	n.s.
Cause13	Accident or injury	21	7.8%	247	92.2%	20	7.5%	247	92.5%	n.s.
Cause14	Pollution	62	23.1%	206	76.9%	33	12.4%	234	87.6%	**
Cause15	Poor medical care	78	29.1%	190	70.9%	71	26.6%	196	73.4%	n.s.
Cause16	Chance or bad luck	149	55.6%	119	44.4%	69	25.8%	198	74.2%	***
Cause17	Own behavior	70	26.1%	198	73.96%	196	73.4%	71	26.6%	***
Cause18	Poor diet	139	51.9%	129	48.1%	249	93.3%	18	6.7%	***

\*\*\*  $p<.001$ , \*\* $p<.01$ , \* $p<.05$

**Table 5.** Average of subscale scores of IPQ-RH-J and causal attributions

	Average of subscale score		T-test
	Breast cancer (n=267)	Diabetes (n=268)	P value
<i>IPQ-RH-J</i>			
Timeline acute/chronic	18.3	21.0	***
Timeline cyclical	9.0	9.0	n.s.
Consequences	15.1	14.5	**
Personal control	8.3	10.5	***
Treatment control	10.5	10.9	*
Illness coherence	9.7	8.8	***
Emotional representations	17.2	15.4	***
<i>Causal attributions</i>			
Psychological attributions	3.8	3.7	n.s.
General risk factors	7.1	6.6	***

\*\*\* p<.001, \*\*p<.01, \*p<.05

research has also shown differences in disease characteristics for duration, sense of self-control, impact on emotions, and causes of disease for breast cancer and diabetes in Japan. Illness cognition may differ according to medical system, cultural belief, sex, social status, country, area, and social background. Usage of IPQ-RH can allow the comparison and understanding of illness cognition according to subject attributes. This will help implement promotion and support measures for healthy behavior based on illness cognition.

One of the major findings of this study is that IPQ-RH has been found to be somewhat universally effective across cultures. On the other hand, as mentioned in the Introduction, it is known that there is “genetic exceptionalism” on genetic information or cause attributions on diseases [6]. This knowledge leads us to ask whether IPQ-RH-J is effective in the setting of genetic counseling. In Japan, discrimination and prejudice against genetic diseases have been a topic of concern [13], and investigations of young healthy people indicated that many subjects had a negative view against “heredity” [14,15]. In future, it will be necessary to determine whether IPQ-RH-J is effective for the understanding of the illness perception of the genetic diseases.

The illness representations change with experience [16], and hence illness perception is expected to change as the results of the provision of information through genetic counseling. Therefore, understanding the social illness perception for genetic diseases can help the medical staffs appropriately comprehend and evaluate the developments and changes of the illness perception of the clients. Previous indexes used to evaluate illness cognition have been limited to the Japanese version of IPQ-R for patients [17]. The potential significance of IPQ-RH-J as an index that objectively evaluates illness cognition of healthy people in general society is substantial. The next challenge is the application of the present scale to congenital abnormality and hereditary disease.

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## Authors' Contributions

H. T-K. contributed to the design and implementation of the research, to the analysis of the results and to the writing of the manuscript. M.I. contributed to the analysis of the results and to the writing of the manuscript. K.Y. contributed to implementation of the research and to the writing of the manuscript.

## Ethics Approval and Consent to Participate

This study was approved by the Medical Research Ethics Committee of Tokyo Medical and Dental University (No. M2018-200). Informed consent was obtained from all respondents before answering the questionnaire.

## Declaration of Interest Statement

The authors declare that they have no competing interests.

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