



## DESCRIPTION OF ILLNESS PERCEPTION IN DIABETIC RETINOPATHY PATIENTS AT RSD DR. SOEBANDI JEMBER

### GAMBARAN PERSEPSI PENYAKIT PADA PASIEN RETINOPATI DIABETIK DI RSD DR. SOEBANDI JEMBER

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#### ABSTRAK

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**Introduction:** Diabetic retinopathy patients have different perceptions about how to take care of themselves. Some have a negative perception of dealing with their illness, which can cause the patient to become depressed, it affects the patient in controlling blood sugar levels, so increasing risk of developing diabetic retinopathy. The negative illness perception causes the patient's lack of awareness to check his eye condition regularly so that it can affect the patient's health condition. This study aimed to analyze the illness perception in patients with diabetic retinopathy at RSD dr. Soebandi Jember.

**Method:** This research was quantitative research using a descriptive design. Respondents in this study were 34 diabetic retinopathy patients obtained by the total sampling technique. Data were collected using the Brief Illness Perception Questionnaire (B-IPQ) and analyzed using univariate data analysis.

**Result:** The results showed an average value of illness perception was 51.44 (SD = 16.85), indicating that diabetic retinopathy was still considered a threat by the respondents. The indicator with the highest value is concern, while the indicator with the lowest value is treatment control. In this study, patients perceive their disease as a threat due to a lack of knowledge about diabetic retinopathy, symptoms of the disease, and patient concerns about their disease.

**Conclusion:** The patient's illness perception needs to be formed to overcome the disease because it can impact the patient's health. One factor influencing illness perception is knowledge because patients with good knowledge can implement the information they have to maintain their health. Providing health education about diabetic retinopathy is needed to improve the patient's perception of the disease.

**Keywords:** Blood Glucose; Diabetic Retinopathy; Illness Perception

#### ABSTRAK

**Pendahuluan:** Pasien retinopati diabetik memiliki persepsi yang berbeda tentang cara merawat diri. Ada yang memiliki persepsi negatif dalam menghadapi penyakitnya, yang dapat menyebabkan pasien menjadi depresi, persepsi negatif dapat mempengaruhi pasien dalam mengontrol kadar gula darah. Peningkatan kadar gula darah dapat menempatkan Anda pada risiko mengembangkan retinopati diabetik. Persepsi penyakit yang negatif menyebabkan kurangnya kesadaran pasien untuk memeriksakan kondisinya secara rutin sehingga dapat mempengaruhi kondisi kesehatan pasien. Penelitian ini bertujuan untuk menganalisis persepsi penyakit pada pasien retinopati diabetik di RSD dr. Soebandi Jember.



**Metode:** Penelitian ini merupakan penelitian kuantitatif dengan menggunakan desain deskriptif. Responden dalam penelitian ini adalah 34 pasien retinopati diabetik yang diperoleh dengan teknik total sampling. Data dikumpulkan dengan menggunakan Brief Illness Perception Questionnaire (B-IPQ) dan dianalisis menggunakan analisis data univariat.

**Hasil:** Hasil penelitian menunjukkan nilai rata-rata persepsi penyakit adalah 51,44 (SD = 16,85), menunjukkan bahwa retinopati diabetik masih dianggap sebagai ancaman oleh responden. Dalam penelitian ini, pasien menganggap penyakitnya sebagai ancaman karena kurangnya pengetahuan tentang retinopati diabetik, gejala penyakit, dan kekhawatiran pasien tentang penyakitnya.

**Kesimpulan:** Oleh karena itu, persepsi penyakit pasien perlu dibentuk untuk mengatasi penyakit tersebut karena dapat berdampak pada kesehatan pasien. Salah satu faktor yang mempengaruhi persepsi penyakit adalah pengetahuan karena pasien dengan pengetahuan yang baik dapat mengimplementasikan informasi yang dimilikinya untuk menjaga kesehatannya. Pemberian pendidikan kesehatan tentang retinopati diabetik diperlukan untuk meningkatkan persepsi pasien terhadap penyakitnya.

**Kata kunci:** Retinopati Diabetik; Gula Darah; Persepsi Penyakit

## INTRODUCTION

Diabetic retinopathy (RD) is one of the complications of diabetes mellitus with visual disturbances that occur due to abnormalities in the retina and vascular system, where there is a progressive microangiopathy characterized by damage and blockage in the blood vessels.<sup>1</sup> Patients with diabetes mellitus with complications of diabetic retinopathy have different perceptions about how to take care of themselves. Some have a terrible perception of dealing with their illness, which can cause the patient to become depressed. It affects the patient in controlling blood sugar levels. Elevated blood sugar levels can increase the risk of further developing diabetic retinopathy.<sup>2</sup> A negative perception of the disease causes the patient's lack awareness to check his eye condition regularly to affect his health.<sup>3</sup> Patients with diabetes mellitus need to have regular retinal examinations. However, many patients still do not comply with further examinations, perhaps due to a lack of knowledge and awareness about diabetic retinopathy.<sup>2</sup> Haloho's research (2017) said that a person's perception is strongly influenced by knowledge. The better the knowledge, the better one's perception is.

Poor diabetes self-management behaviors such as uncontrolled blood glucose, knowledge about complications of diabetic retinopathy, and depression can influence the development of more severe diabetic retinopathy.<sup>4</sup> In Peng's (2018) study with 275 patients with diabetes mellitus, various perceptions of complications of diabetic retinopathy were shown. The results showed that around 30% of patients knew that they had to have an eye examination to find out their disease, 45.8% of patients did not see the risk factors for diabetic retinopathy, 43% of patients indicated that they were not aware of the need for an eye examination with the most common reason,

namely 18.1% of patients believed that their eyes are in good health. In Mkhombe's (2021) study with 149 patients, the results showed that 71.8% of patients understood that diabetic retinopathy could occur in people who had long suffered from diabetes mellitus, 83.2% of patients took eye health seriously so that they had an eye examination on schedule because they knew A complication that occurs is diabetic retinopathy.

A person experiencing a disease will form his own beliefs and views that can affect how he responds to his illness.<sup>6</sup> Various angles of a person's perspective related to beliefs about a disease that individuals make to interpret a condition based on the information that a person has been called illness perception. Illness perception can influence a person in solving health problems and choosing the method to control or treat the disease.<sup>7</sup> The attitude of the patient's response related to the signs and symptoms of the disease he is experiencing is from the source of information. The information obtained is then interpreted as cognitive and emotional understanding to form perceptions. Having illness perception is a person's first step in the process of coping mechanisms to deal with illness and seek treatment.<sup>8</sup> From the cognitive and emotional processes influenced by external and internal factors, illness perception is formed.<sup>7</sup>

One form of a patients initial coping with the disease is perception. A good perception will produce an adaptive response in facing and seeking treatment for the disease. In contrast, a lousy perception will have a maladaptive response that can hurt the patient, one of which is depression.<sup>8</sup> In addition, patients with poor illness perception usually refuse to take treatment, and it will be difficult to change unhealthy lifestyle habits.<sup>9</sup> Based on this background, the researcher intends



to research the description of illness perception in diabetic retinopathy patients at RSD dr. Soebandi Jember.

## METHODS

The research design used in this research is descriptive. In this study, the population used was diabetic retinopathy patients who visited the eye clinic of RSD dr. Soebandi Jember in 2021, totaling 44 patients. The number of samples will be used is 44 diabetic retinopathy patients who checked themselves at the eye clinic of RSD dr. Soebandi Jember in 2021, but after the study was conducted, as many as ten patients dropped out because they were included in the exclusion criteria, namely diabetic retinopathy patients who have physical limitation such as deaf, mute, and the patient died, so the total number of respondents in this study was 34. In this study, the sampling technique used is total sampling. Data collection was carried out from 23 May to 15 June 2022.

The instrument used in this study was the B-IPQ questionnaire to measure the patient's perception of his illness by Broadbent 2006. The B-IPQ questionnaire consists of 9 questions divided into eight questions using a Likert scale

with a scale of 0-10 and 1 question in descriptive form. The questions are divided into 5 question items assessing the cognitive representation of disease, consequences, timeline, treatment control, identity, and personal control, 3 question items assessing the emotional representation of disease, namely comprehensibility, concern, and emotional, and 1 question item regarding responses to causes. Disease by asking questions about the three factors that cause disease. Data analysis was performed by univariate data analysis.

This research has received an ethical statement from the ethics committee of the Faculty of Nursing, University of Jember which was issued on April 13, 2022, with letter number 062/UN25.1.14/KEPK/2022. The researcher asked for research permission from LP2M University of Jember, Jember National Unity and Politics Agency, and RSD dr. Soebandi Jember. Data was collected by visiting respondents' homes based on data obtained from the patient's medical records.

## RESULT

### Characteristics

**Table 1.** Characteristics Data of Respondents Based on Age in Diabetic Retinopathy Patients at RSD dr. Soebandi Jember (June 2022; N = 34)

Characteristics	Mean ( $\pm$ SD)
Age	51,53 (9,59)

**Table 2.** Characteristics Data of Respondents Based on Gender, Education, Marital Status, Occupation in Diabetic Retinopathy Patients at RSD dr. Soebandi Jember (June 2022; N = 34)

Characteristics	F (%)	Characteristics	F (%)
Gender		Marital status	
Male	10 (29,4)	Not married	1 (2,9)
Female	24 (70,6)	Married	28 (82,4)
Education		Divorced	5 (14,7)
Did not go to school	1 (2,9)	Occupation	
Primary school	19 (55,9)	Not working	22 (64,7)
Junior high school	6 (17,6)	Farmer	5 (14,7)
Senior high school	6 (17,6)	Laborer	1 (2,9)
Diploma	0 (0)	Entrepreneur	3 (8,8)
Bachelor	2 (5,9)	Employee	2 (5,9)
		Civil servant	1 (2,9)

F = Frequency

Table 1 for numerical data presented in the form of an average value shows the average age of the respondents, which is 51.53 years. Table 2 shows that more respondents were female (70.6%) than male (29.4%). The highest level of education

in elementary school graduates (55.9%). The majority of respondents' marital status is married (82.4). Most of the respondents do not work (64.7%).



## Illness Perception

**Table 3.** Value of Disease Perception in Diabetic Retinopathy Patients (June 2022; N: 34)

Variable	Mean	SD
Illness Perception	51,44	16,85

Table 3 shows the average illness perception value of  $51.44 \pm 16.85$ , which means that diabetic retinopathy is considered a threat by the respondents.

**Table 4.** The value of the disease perception indicator in diabetic retinopathy patients for Indicators No. 1 to 8 (June 2020; N: 34)

Indicators	Mean	SD
Consequences	7,79	2,22
Timeline	6,44	3,31
Personal Control	3,94	3,42
Treatment Control	6,03	3,38
Identity	6,56	2,77
Concern	7,88	2,86
Comprehensibility	3,56	3,39
Emotional	6,29	3,06

Table 4 shows the highest indicator value, namely concern, with a mean value of  $7.88 \pm 2.86$ , while the lowest indicator is the treatment control indicator, with an average value of  $3.56 \pm 3.39$ .

**Table 5.** Value of Disease Perception Indicators in Diabetic Retinopathy Patients for Indicator No. 9 concerning the Main Factors Causing Diabetic Retinopathy Based on Diabetic Retinopathy Patients' Perceptions

Causes of Diabetic Retinopathy	Frequency (F)	Percentage (%)
Diabetes mellitus	28	82,3
Hypertension	13	38,2
Diet	7	20,5

Table 5 shows that the three main causes of diabetic retinopathy are diabetes mellitus (82.3%), hypertension (38.2%), and diet (20.5%).

## DISCUSSION

The results of a study conducted on 34 diabetic retinopathy patients obtained a mean value of  $51.44 \pm 16.85$ , which means that diabetic retinopathy patients in this study had the perception that diabetic retinopathy was considered threatening. A total score above 40

indicates the disease is viewed as a threat because a value of 40 is the middle limit of the total score between 0 to 80. The illness perception questionnaire has a minimum score of 0 and a maximum score of 80. In total, the overall score can describe the extent to which the patient considers the disease threatening or not.<sup>10</sup>

Several factors influence illness perception. The first factor is the level of knowledge. In this study, most patients had a low level of education, with a total of 20 respondents (58.8%). The story of education can affect a person's level of knowledge, one of which is in the health sector. The higher a person's education, the easier it is to receive and process information into behavior in maintaining his health.<sup>11</sup> Common knowledge is due to the lack of available information related to health, especially about preventing complications of diabetic retinopathy, thus affecting the patient's ignorance of the signs, symptoms, and how to handle them.<sup>12</sup>

The second factor is experience. Experience is one of the factors that influence perception. Experience will make a person better prepared for the possibilities that will happen to him.<sup>13</sup> A person's experience with a disease that has been suffered can give rise to perceptions related to his illness. The perceptions are formed to make them understand the steps that must be taken to overcome the disease.<sup>14</sup> The experience that a person has will affect the formation of perceptions. A good perception can influence a person in preventing disease.<sup>15</sup> Based on the results obtained on experience indicators related to symptoms experienced as a result of diabetic retinopathy with an average of 6.56, respondents perceive the disease as a threat. The researcher assumes that there are still many respondents who have no experience with the symptoms of the disease, both personal and family experiences so that it affects the respondent's perception of diabetic retinopathy.

Furthermore, the third factor that influences perception is gender. In giving perception to an object, one of them is influenced by gender. Gender differences can form different perceptions, affecting different responses between women and men in stimulating the thing seen.<sup>16</sup> That gender does not directly affect a person's perception but can affect emotion which is one component of perception. Men are usually more able to control their emotions than women.<sup>17</sup> Women express more of the conditions they are experiencing in emotional forms such as sadness and fear.<sup>18</sup> In this study, more respondents were female (76%), and the average value of illness perception on the emotional indicator was 6.29. Researchers assume that gender affects illness perception, especially on



emotional indicators, because women are more expressive in responding to their illness.

The illness perception questionnaire consists of 9 indicators with eight likert scale assessment questions. The questions that exist are about consequences, timeline, personal control, treatment control, identity, concern, comprehensibility, and emotional. One last question in the form of essay questions with questions about the three factors that cause disease.

In this study, the indicator with the highest value was the concern indicator with an average value of  $7.88 \pm 2.86$ , meaning that the concern indicator for diabetic retinopathy was considered threatening. This indicator explores how much the patient is worried about diabetic retinopathy. Patients who suffer from diabetes mellitus for a long time with complications of diabetic retinopathy have deep concerns because their illness causes their health to become increasingly deteriorating, so that it interferes with daily activities.<sup>19</sup> Complications caused by diabetes mellitus can trigger psychological changes in patients, such as patients feeling worried about their health to the point of causing symptoms of depression.<sup>20</sup> Worry is a condition of a person in an emotional state that is experienced subjectively.<sup>21</sup> In patients with diabetic retinopathy, psychological changes that occur cause prolonged depression due to the burden of carrying out health care and visual disturbances that can progress to vision loss.<sup>22</sup> In the book, Potter & Perry (2005) states that someone with a disease will experience emotional stress in the form of worry, which can cause bad sleep habits that can affect a person's quality of life.<sup>23</sup> Based on this, the researcher assumed that diabetic retinopathy was considered a threat because the patient was concerned about the disease that could affect the patient's health status and vision.

While the indicator with the lowest value is the treatment control indicator, with an average value of  $3.97 \pm 3.38$ , meaning that the respondent's treatment control indicator considers diabetic retinopathy, not a severe threat. The B-IPQ questionnaire uses a scale from 0-10 to assess each indicator, where higher scores indicate stronger perceptions.<sup>24</sup> This indicator explores how much the treatment received can help cure the disease.

Treatment that can be done to control mild to moderate non-proliferative diabetic retinopathy is to control risk factors that can increase the severity of diabetic retinopathy, such as controlling blood sugar levels and blood pressure. Meanwhile, patients with severe non-proliferative diabetic retinopathy can undergo treatment with pan-retinal

laser photocoagulation therapy.<sup>25</sup> The most important treatment for diabetic retinopathy patients is to control blood sugar levels by using insulin or oral medication.<sup>26</sup> Control and prevention of further decreased vision can be done by increasing knowledge and awareness about diabetic retinopathy, as well as a positive attitude towards treatment by routinely controlling eye examinations as recommended by doctors.<sup>27</sup> The study results indicate that the respondent's illness perception on the treatment control indicator is not a severe threat. The researcher assumes that this happens because the respondent has control over treatment, and the treatment provided by health workers helps cure diabetic retinopathy, thus shaping the patient's perception that the treatment is being administered, can cure the disease.

In the cause indicator, three main factors cause diabetic retinopathy, namely diabetes mellitus, hypertension, and diet. The first factor is diabetes mellitus. Anugrah's research (2013) found that as many as 70.83% of patients with diabetes mellitus were diagnosed with diabetic retinopathy. This is because diabetic retinopathy patients have high lipid content which causes endothelium dysfunction through local inflammation and the formation of free radicals that lead to oxidative stress and changes in blood vessel walls. Damage to the permeability of retinal blood vessels caused by endothelial dysfunction in patients with diabetes mellitus causes diabetic retinopathy.<sup>29</sup> In addition, the prolonged duration of suffering from diabetes mellitus is also a risk factor for diabetic retinopathy. This occurs due to prolonged exposure to hyperglycemia which can increase the risk of vascular injury, causing diabetic retinopathy.<sup>30</sup>

The second risk factor is hypertension. In the research of Utami et al. (2017), it was found that from 75 respondents, 70 respondents suffered from hypertension which was divided into 25 respondents who experienced prehypertension, 23 respondents who experienced stage I hypertension, and 22 respondents who experienced stage II hypertension. Another study by Mahmudah et al. (2020) found that 58.7% of diabetic retinopathy patients suffered from hypertension. Hypertension is a risk factor for the development of diabetic retinopathy. This is because an increase in blood pressure can cause endothelial stress with the release of VEGF, which alters retinal autoregulation, increasing blood perfusion pressure.<sup>29</sup> Patients with diabetes mellitus with hypertension have a 2-fold increased risk of developing diabetic retinopathy compared to diabetic patients with normal blood pressure. Hypertension can cause morphological changes in retinal blood vessels.<sup>30</sup> To help prevent the development of diabetic retinopathy, what can be done is to control blood pressure.<sup>32</sup>



The third risk factor is diet. The development of diabetic retinopathy can be influenced by non-adherence to diet in patients with diabetes mellitus, such as the type, dose, and schedule of food consumed.<sup>33</sup> Controlled diabetes mellitus in diabetic retinopathy patients by adhering to minimum drugs, maintaining a diet, and doing physical activity can slow down vision loss.<sup>34</sup> Patients who do not maintain a good diet will increase blood sugar levels, causing hyperglycemia, one of the factors for diabetic retinopathy.<sup>35</sup> Diabetic retinopathy occurs due to continuous exposure to hyperglycemia which causes chemical and biological changes in the endothelium of blood vessels.<sup>36</sup> Examination of blood sugar levels can determine whether the patient has controlled blood sugar levels. Controlling blood sugar levels can prevent an increase in the severity of diabetic retinopathy.<sup>37</sup> The same statement in the research of Hainsworth et al. (2019) said that intensive glycemic control is very important in reducing the development of diabetic retinopathy.

## CONCLUSION

In the illness perception variable, the average value was  $51.44 \pm 16.85$ , which means that the diabetic retinopathy patients in this study had the perception that diabetic retinopathy was considered threatening. The highest score was obtained on the concern indicator with an average of 7.88, while the lowest score on the treatment control indicator with an average of 3.97.

## SUGGESTIONS

### For the Nursing Profession

The role of nurses as educators needs to be increased by providing health education, especially to diabetic retinopathy patients so that patients can understand more about their disease, what treatment should be carried out, and can increase a good perception of their disease.

### For the Community or Respondents

Increasing a good perception of the disease needs to be done by diabetic retinopathy patients because it can improve the patient's quality of life. Ways that can be done are to seek information about diabetic retinopathy, increase adherence to control blood sugar levels, and routinely carry out eye examinations according to doctor's recommendations.

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