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Health Literacy of Individuals with Visual Impairments in Yogyakarta Province, Indonesia

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ABSTRACT

Background: Individuals with visual impairments tend to have low health outcomes. Exploring health literacy among this group can provide a basis for designing effective strategies for healthcare services that assist this special population.

Objectives: This study aimed to determine the health literacy level of individuals with visual impairments.

Methods: A cross-sectional study was employed in this study. We administered a survey using the Health Literacy Scale European Union Q16 (HLS-EU-Q16) Indonesian version questionnaire to individuals with visual impairments in Yogyakarta. Members of two Non-Government Organisations (NGOs), namely *Ikatan Tunanetra Muslim Indonesia*/Indonesian Muslim Blind association (ITMI) and *Persatuan Tuna Netra Indonesia*/Indonesian Blind Association (Pertuni) were invited as respondents using a purposive sampling method. Data was collected during the NGOs regular meetings in August and September 2019, which took place in some members' houses or public places throughout Yogyakarta province.

Results: A total of 95 eligible respondents who consented to join the study had a health literacy index of 31.29 ± 8.91, classified as problematic, with an index range between 3.13 and 50.00 (inadequate to excellent).

Conclusion: Our findings revealed that individuals with visual impairments have problematic health literacy and face multiple determinants to improve their health literacy. This condition requires pharmacists and other health professionals to be aware of it and to develop an appropriate strategy to deal with it comprehensively.

Keywords: Health Literacy; HLS-EU-Q16; Visual Impairment; Yogyakarta.

INTRODUCTION

Health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions.[1] Health literacy is an important factor in achieving optimal health outcomes. Low health literacy will lead to poor self-management skills, resulting in non-compliance to treatment, lower health outcomes, and higher medical costs.[2] Low health literacy also affects low disease self-management and individual health behaviors. Individuals with low health literacy are more likely to present with advanced illness, resulting in delayed diagnosis and treatment and poorer outcomes.[3]

In Indonesia, studies on public health literacy have been initiated in several areas in Jakarta, Semarang, and Yogyakarta Provinces since 2013. The results of these studies presented a low level of public health literacy. Out of 141 high school students, 114 of them have a low level of health literacy.[4] About 67% of 100 patients who visited community health centers in Yogyakarta have a low level of health literacy.[5] For specific populations such as individuals with diabetes mellitus, the level of health literacy is categorized as inadequate level.[6,7] These studies showed the consistent challenges that Indonesia has to overcome in health literacy.

However, those results remain inconclusive, because none of them included minorities and vulnerable groups. Minorities and vulnerable groups such as indigenous peoples, people with disabilities, and those with certain chronic illnesses have poor health status and receive lower quality care than the general population. People with disabilities are more likely to have poor health and higher mortality because of their underlying impairment or health condition, higher prevalence of risk factors (eg, malnutrition), and barriers to access healthcare services.[8] Along with a higher risk of falls, fractures, injuries, poor mental health, cognitive deficiencies, and social isolation, people with visual impairment are also more likely to face limitations in their independence, mobility, and academic performance.[9]

Health literacy among people with visual impairment is underrepresented since the health information was not designed for them. Individuals with visual impairment (VI) use a multitude of mediums to access and understand health information. Rarely, health information is designed considering tactile information or braille format as a source of information.[10] Interventions in public health promotion programs including health literacy are also barely designed for specific populations.[11] Evidence of health literacy among minorities and vulnerable groups is difficult to find. Literature on interventions for the visually impaired population remains limited.

Health literacy levels of people with disabilities needs to be assessed by pharmacists or health professionals because they are more susceptible to have poorer health outcomes compared to those without disabilities.[12] Measuring health literacy and identifying the strengths and weaknesses of health literacy aspects will provide evidence of the specific needs of individuals with visual impairment. Furthermore, it can be basic information for health professionals in developing effective and strategic designs for health literacy interventions. With the improvement of health literacy among individuals with visual impairment, it is ultimately hoped that there will be better health outcomes and enhancements in the health system for becoming more inclusive.

METHODS

Study design

A cross-sectional survey was employed to determine the health literacy levels of individuals with visual impairment in Yogyakarta Province. A paper-based, researcher-administered questionnaire was used.

Study Participants

Based on data from the Indonesia Central Bureau of Statistics in 2016, the number of visually impaired individuals in Yogyakarta was reported to be 2,198 people.[13] We recruited individuals with visual impairments purposively who met inclusion and exclusion criteria to join our study with the help of two Non-Government Organisations (NGOs): *Ikatan Tunanetra Muslim Indonesia*/Indonesian Muslim Blind association (ITMI) and *Persatuan Tuna Netra Indonesia*/Indonesian Blind Association (Pertuni). The inclusion criteria were individuals with visual impairments as defined by WHO or self-reported limitations as blind or low vision, more than 18 years old, lived in Yogyakarta, have accessed any health care services, able to communicate, and willing to join the study. We excluded respondents who had multiple disabilities (visual impairments and/or other disabilities such as deafness, speech impairment, and physical disabilities).

Study instruments

In this study, we used the Health Literacy Survey-European Union-Questionnaire 16 (HLS-EU-Q16) Indonesian version, a standardized questionnaire to assess our respondent's health literacy index. The HLS-EU-Q16 is the short version of HLS-EU-Q47 and was developed by the HLS-EU consortium. The questionnaires have been widely used in many countries, translated into many languages including Bahasa Indonesia, and are considered public domain.[14,15] It is recommended to use the short-form questionnaire in studies with vulnerable populations.[16] The HL-EU-Q16 has sixteen questions which are divided into three domains, seven questions on the healthcare domain, five questions on the disease prevention domain, and 4 questions on the health promotion domain.[14] Each domain is distributed in the staging process on how individuals' access, understand, appraise, and apply the information on health. The matrix of HLS-EU-Q16 can be seen in Table I.

Table I. HLS-EU-Q16 survey short version Matrix based on the HLS-EU Consortium 2012, Measurement of health literacy in Europe: HLS-EU-Q47; HLS-EU-Q16; and HLS-EU-Q86 [16,17]

HLS-EU-16 survey matrix	Finding Information on Health (FHI)	Understanding Information on Health (UHI)	Appraising / Judging Information on Health (JHI)	Applying Information on Health (AHI)
Domain 1 Health Care (HC)	Q1, Q2	Q3, Q4	Q5	Q6, Q7
Domain 2 Disease Prevention (DP)	Q8	Q9, Q10	Q11	Q12
Domain 3 Health Promotion (HP)	Q13	Q14, Q15	Q16	

Note: Q=question

Study Setting and Data collection

Yogyakarta Province was selected as study site because Yogyakarta committed to be inclusive for person with visual impairment and have several support systems, such as local regulation for persons with disabilities number 4, 2019 representing the rights of persons with disabilities and the presence of some NGOs which specifically support the needs of persons with visual impairments. Two NGOs registered in Yogyakarta, Pertuni and ITMI, committed to the well-being of their members with visual impairments. Pertuni was established on January 26, 1966,[18] and serves about 250 adult members (the requirement to become a Pertuni member is at least 17 years old) (Pertuni organizer, oral interview, August 2019). ITMI was established in around 1967 and focused more on the religious improvement of its members. We collaborated with these two NGOs to recruit respondents and distributed our questionnaire. Data were collected during their regular meetings in August and September 2019, which took place in some members' houses or public places throughout Yogyakarta province. Questionnaires were read out to the respondents and administered with the help of seven enumerators (pharmacist program students). These seven enumerators have been trained in how to engage with individuals with VI.

Data Analysis

Each question was scored on a 4-point Likert scale based on how easy the participants perceived to do actions asked in the questionnaire (1=very difficult, 2=fairly difficult, 3= fairly easy, 4=very easy). We assessed the health literacy of our respondents using the equation below.[14,16]

$$\text{Index} = (mean - 1)\frac{50}{3}$$

Index = health literacy index

Mean = the mean total health literacy score for each individual.

1 = the minimum health literacy score that can be obtained.

3 = the range of the mean score.

50 = the maximum health literacy score that can be obtained.

The result of the index determined the level of health literacy of each individual and categorized into four groups: (1) inadequate if the score is between 0 and 25, (2) problematic if the score is >25-33, (3) sufficient if the score is > 33-42, and (4) excellent if the score is > 42-50.[14,16] Fisher exact test was applied to see whether there is significant difference between male and female respondents. Jamovi 2.6.23 was used to organize and analyze the data. The health literacy index was presented in general health literacy (Gen-HL) and in each domain (1) Health Care Health Literacy (HC-HL); (2) Diseases Prevention Health Literacy (DP-HL); (3) Health Promotion Health Literacy (HP-HL).

RESULTS AND DISCUSSION

A total of 95 participants agreed to participate in the study. Their age range of the respondents is 21 to 67 years, with an average age of 44 years. The characteristics of the respondents were quite varied in terms of gender, education, income, and health insurance (Table II).

The majority of persons with visual impairments (84.20%) have a low to medium level of education. They participated in massage skills training to improve their competencies. This condition also affects the type of work they do. Most of them are owners or masseurs of massage services of the visually impaired (*pijat tuna netra*). Due to this situation, their income was equivalent to the Regional Minimum Wage of Yogyakarta or even lower (67.40%). Whereas, Yogyakarta Regional Minimum Wage is the lowest among 38 provinces in Indonesia.[19]

Table II. Characteristics of Respondents (N = 95)

Category	Mean± SD or N (%)
Sex	
Male	52 (54.70)
Female	43 (45.30)
Age (years)	44.24 ± 10.57
Education*	
Low-Middle	80 (84.20)
High	15 (15.80)
Household Income	
Below Yogyakarta Minimum Wage**	64 (67.40)
Upper Yogyakarta Minimum Wage	31 (32.60)
Health Insurance Ownership	
Yes	68 (71.60)
No	27 (28.40)
Distance from health facilities (in kilometers)	1.29 ± 1.60

*Low-middle education includes elementary, junior, high school, or did not attend school. High education includes university level. **Yogyakarta Province's Minimum Wage in 2019 was 1.570.923.[19]

Table III. Classification of Health Literacy Index (N = 95)

Category	Mean± SD or N (%)
Health Literacy Index of Individual with Visual Impairment	31.29 ±8.91
Inadequate	23 (24.20)
Problematic	38 (40.00)
Sufficient	23 (24.20)
Excellent	11 (11.60)

In 2014, Indonesia applied a universal health coverage system by establishing a social security agency for health (BPJS). BPJS has two schemes of insurance membership, non-contributory modality for the poorer including people with disabilities (PBI) and contributory modality for salaried workers, non-salaried workers, and non-employees as well as their family members (non-PBI). In 2017, 1.2 million of persons with disabilities have access to PBI, and approximately 20,404 indiv

iduals received assistive devices from 2015 to 2017.[20] About 90.30% of Indonesians have BPJS and 60.39% of them are covered under the PBI scheme.[21] About 71.60% of respondents also reported having health insurance, whether it be BPJS Insurance, while some others stated that they do not have health insurance (28.40%). Some of them who have health insurance faced difficulties in managing the membership, leading to their membership not being renewed.

In terms of the distance of respondents' residences to health service facilities, generally, respondents are located close to the community health centers in their area. However, although several characteristic variables explored in this study are factors that are expected to influence health literacy levels, including distance to health facilities, there is a specificity for individuals with visual impairments, namely that distance may not always correlate with ease of access to health services.

Individuals with visual impairments have a diverse level of health literacy. From 95 individuals who were willing to participate, data on the health literacy index was obtained from an index range between 3.13 and 50.00. The health literacy index presented mostly in problematic levels (Table III). It is consistent with another study in Denmark among populations with chronic retinal diseases.[22]

Just like the general population, health literacy levels are also fairly evenly distributed across all index categories, although they all share a problematic average index.[5,23–25] In 2019, Roidatin and colleagues studied the level of health literacy among the hypertensive population, and the results showed that hypertensive patients also had a problematic health literacy index.[26]

Table IV. Classification of Health Literacy Index Per Domain (N = 95)

Domain	Category	N (%)
Healthcare (Question 1–7)	inadequate	21 (22.10)
	problematic	18 (18.90)
	sufficient	42 (44.20)
	Excellent	14 (14.70)
Disease Prevention (Question 8-12)	inadequate	30 (31.60)
	problematic	25 (26.30)
	sufficient	22 (23.20)
	excellent	18 (18.90)
Health Promotion (Question 13-16)	inadequate	31 (32.60)
	problematic	23 (24.20)
	sufficient	30 (31.60)
	excellent	11 (11.60)

Table V. Male vs Female Visual Impairment's Health Literacy (N = 95)

Health Literacy Index	Male (n=52)	Female (n=43)	Test Statistic*
Inadequate	9	11	P=0.142
Problematic	27	14	
Sufficient	9	14	
Excellent	7	4	

Note: N is the number of total respondents. n is the number of male/females. *Fisher exact test

Although it is evident that the health literacy of most respondents is problematic (Table III), we analyzed each domain to see the weight of the health literacy (Table IV). Surprisingly, most of the respondents on domain disease prevention and health promotion are reported inadequate. But significant numbers of respondents (44.20%) demonstrate sufficient healthcare domain. These findings underline that visual impairment residents are capable of accessing, understanding, and implementing their disease treatment information rather than the prevention and health promotion.

Following up the findings on Table IV, we breakdown into two groups, female and male, and we found that male respondents almost double contributed to problematic health literacy (Table V). Similarly, this result is inline among the migrant population,[27] but there is paucity in the gender-specific studies among the visual impairment population. Future gender-specific study will be beneficial by following up this finding.

We mapped out the health literacy process in table VI, VII, and VIII in detail to identify in which stage that the health literacy of Yogyakarta visual impairment people is. The process from finding information (FHI), understanding information (UHI), appraising the information (JHI), and finally applying the information on health (AHI).

Health Care Health Literacy (HC-HL)

In this domain, individuals with visual impairment were mapped out based on how they receive and process health information starting from finding health care information up to applying health-care-related information. About 44% of them have sufficient health literacy. From Table VI, individuals with visual impairment have strong capacity in finding the information but they have impeded in understanding the health professional's advice which implicate the low capacity in appraising the information and executing the action. This result is consistent that many individuals with visual impairment perceived that self-administration of medication was a challenging task.[28]

Table VI. Health Care Health Literacy (HC-HL) (n = 95)

HLS-EU-Q16	HLS-EU-Q47	Matrix (original version)	How easy would it be to:	FHI	UHI	JHI	AHI
Q1	Q1.2	HC-FHI 1.1.2	find information on treatments of illnesses that concern you	3.02			
Q2	Q1.4	HC-FHI 1.1.4	find out where to get professional help when you are ill	3.35			
Q3	Q1.5	HC-UHI 1.2.1	understand what your doctor says to you		2.99		
Q4	Q1.8	HC-UHI 1.2.4	understand your doctor's or pharmacist's instructions on how to take a prescribed medicine		2.94		
Q5	Q1.11	HC-JHI 1.3.3	judge when you may need to get a second opinion from another doctor			2.65	
Q6	Q1.13	HC-AHI 1.4.1	use information the doctor gives you to make decisions about your illness				2.69
Q7	Q1.16	HC-AHI 1.4.4	follow instructions from your doctor or pharmacist				2.94

*Q=Question; HC-FHI=Healthcare-Finding Information on Health; HC-UHI=Healthcare-Understanding Information on Health; HC-JHI=Healthcare-Judging Information on Health; HC-AHI=Healthcare-Applying Information on Health

Table VII. Disease Prevention-Health Literacy (DP-HL) (N = 95)

HLS-EU-Q16	HLS-EU-Q47	Matrix (original version)	How easy would it be to:	FHI	UHI	JHI	AHI
Q8	Q1.18	DP-FHI 2.1.2	find information on how to manage mental health problems like stress or depression	2.55			
Q9	Q1.21	DP-UHI 2.2.1	understand health warnings about behavior such as smoking, low physical activity and drinking too much		3.23		
Q10	Q1.23	DP-UHI 2.2.3	understand why you need health screenings		2.74		
Q11	Q1.28	DP-JHI 2.2.3	judge if the information on health risks in the media is reliable			2.84	
Q12	Q1.31	DP-AHI 2.4.3	decide how you can protect yourself from illness based on information in the media				2.60

*Q = Question; DP-FHI = Disease Prevention - Finding Information on Health; DP-UHI = Diseases Prevention - Understanding Information on Health; DP-JHI = Disease Prevention - Judging Information on Health; DP-AHI = Disease Prevention - Applying Information on Health.

Diseases Prevention Health Literacy (DP-HL)

Individuals with visual impairments have inadequate health literacy on disease prevention (31.60%). They are aware of unhealthy behavior, but they have difficulties finding the information about mental health management and mitigate disinformation and/or misinformation on health. These findings showed the vulnerability of individuals with visual impairment in health prevention (Table VII). The vulnerability of VI presented in all aspect of finding, understanding, judging, and applying the information. In addition, they tend to be excluded from the health information design in disease prevention. There is no available access to public health programs in auditory or tactile information therefore this condition coupled with the limited exposure alternative medium for public health messages which could not generally be accessed such as posters on the wall.[29]

Table VIII. Health Promotion-Health Literacy (HC-HL) (N = 95)

HLS-EU-Q16	HLS-EU-Q47	Matrix (original version)	How easy would it be to:	FHI	UHI	JHI	AHI
Q13	Q1.33	HP-FHI 3.1.2	find out about activities that are good for your mental well-being	2.58			
Q14	Q1.37	HP-UHI 3.2.1	understand advice on health from family members or friends		3.04		
Q15	Q1.39	HP-UHI 3.2.3	understand information in the media on how to get healthier		2.86		
Q16	Q1.43	HP-JHI 3.3.3	judge which everyday behavior is related to your health			3.02	

*Q = Question; HP-FHI = Health Promotion - Finding Information on Health; HP-UHI = Health Promotion - Understanding Information on Health; HP-JHI = Health Promotion - Judging Information on Health.

Health Promotion Health Literacy (HP-HL)

Inadequate health literacy of the individuals with visual impairments on health promotion was captured in this measurement (32.60%). Some of them have sufficient (31.60%) capacity. This finding presented the uneven distribution of health literacy in health promotion among them. They have support groups (ITMI and Pertuni) in sharing information on advice for health, but their understanding of healthy behavior messages tends to result in low capacity.

However, this study has limitation. The research was executed in 2019. Previously, we conducted a focus group discussion following the survey; however, it occurred only once and could not be continued due to COVID-19. In 2024, we sought relevant studies regarding visual impairment among the Indonesian population but have yet to identify any pertinent research on this subject. We believe that publishing our work enhances the evidence for health-inclusive programs aimed at addressing visual impairments and improving health literacy.

CONCLUSION

Based on HLS-EU-Q16 measurement, health literacy levels among individuals with visual impairments are problematic. Knowing and understanding the health literacy index of the visual impairment population in Yogyakarta may benefit healthcare professionals for planning concrete interventions. The findings in this study indicated the need for improvement in health literacy for individuals with visual impairments is of utmost urgency. This finding can be a basic information for pharmacists and health professionals to develop comprehensive strategies for visually impaired patients to achieve good health literacy. Furthermore, this study increases the evidence for inclusive policies design or health services in Yogyakarta.

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STATEMENT OF ETHICS

This research has received approval from the Medical and Health Research Ethics Committee, Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada with the number KE/FK/1118/EC/2019. We ensure our respondent's personal data is anonymous and confidential. All respondents received information verbally. Respondents who agreed to join this study signed or thumbprinting the informed consent form.

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