



Quality of life among patients from urban and rural areas with advanced age-related macular degeneration assessed using the NEI-VFQ-25

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Abstract

Objective. The aim of the study was to explore the influence of exudative age-related macular degeneration on the quality of life of patients from urban and rural areas.

Materials and method. The retrospective study included 144 Polish Caucasians with exudative age-related macular degeneration, treated with anti-VEGF, recruited from Department of Medical Retina in Lublin between March and June 2017. Clinical assessment included age, gender, visual acuity, complete ophthalmic examination, fundus fluorescein angiography and optical coherence tomography, medical history and the NEI VFQ-25 questionnaire.

Results. The mean age of the study group was 76.73±12.3 years, average time of AMD was 4.24±4.1 years. 21.5% of patients reported comorbidities such as hypertension, cardiovascular disease, diabetes mellitus. 99 (68.75%) lived in a city, while 45 (31.25%) in a village. There was a tendency of females to complain more than males about moderate and severe discomfort and pain (p=0.09). Most of the patients did not drive a car before the onset of the disease (female vs. male: 81% vs 62.9%; p=0.01). 62.8% males and 25.8% females gave up driving (p= 0.003), whereas significantly more males gave up driving' and 25% of villagers gave up driving (p=0.07). The parameter because of the eyesight – female vs. male: 50% vs. 20.8%; p=0.03. There was a tendency of village respondents to complain more often about extreme difficulty in reading newspapers, street signs or the names of stores than (p=0.08). 44.2% city residents. Rural patients felt to achieve much less because of their eyesight, which was not observed in patients from the city (p=0.06).

Conclusions. The place of residence and gender influenced perception of the disease in exudative form of age-related macular degeneration.

Key words

AMD, rural areas, urban areas, quality of life

INTRODUCTION

Age-related macular degeneration (AMD) is the leading cause of irreversible visual impairment and legal blindness in developed countries, affecting mainly people older than 60 years. Approximately 30 million people nowadays suffer from AMD, accounting for 8.7% of the whole population worldwide. It is estimated that the number of AMD affected patients will increase to 288 million by 2040 [1].

AMD is a progressive disease that severely impairs central vision. There are two clinical forms of AMD: dry AMD, characterised by retinal pigment epithelium alterations, drusen, atrophy and exudative AMD. In particular, the exudative form of AMD, complicated by choroidal neovascularization, presents a severe vision-affecting condition in which the subretinal neovascular membrane progressively destroys the retinal layers. Intravitreal anti-VEGF (vascular endothelial growth factor) agents are used for treatment of this type of disease. AMD exerts an impact on many aspects of everyday functioning and independent

life, such as ability to read, shopping, driving and cooking for oneself [2]. Patients with advanced stages of AMD may also suffer emotional distress and depression, anxiety and social isolation which finally result in reduced health-related quality of life (HRQoL) [3, 4, 5].

In 2001, the National Eye Institute Visual Functioning Questionnaire (NEI-VFQ-25) scale was developed to determine QoL among patients with chronic blindness, including AMD. The scale provides an evaluation of the impact of visual impairment on the emotional wellbeing, social relationships and daily activities of patients with chronic blindness [6].

Although the effects of exudative AMD on the quality of life have been studied extensively in well-developed countries, no data exists comparing the quality of life of patients with AMD from urban and rural regions. Different social habits, everyday activities and cultural characteristics in different communities may lead patients to be influenced psychologically in different manners from the same disease.

A good understanding by others can potentially improve AMD patients' quality of life by, for example, increasing empathy for persons affected by AMD, allowing cohabitants to provide practical help in everyday activities and social life.

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OBJECTIVE

The aim of the study is to explore the influence of life experience and perception of AMD patients from urban and rural areas of the Lublin Region of eastern Poland. The QoL was assessed by NEI-VFQ-25. Obtained results can help to understand the possible different needs and habits of AMD-affected patients from two different environments.

MATERIALS AND METHOD

The retrospective study included 144 Polish Caucasians with exudative age-related macular degeneration, treated with anti-VEGF, recruited in the Department of Medical Retina at the Ophthalmic Clinic in Lublin between March – June 2017. Exudative AMD was diagnosed and defined as occurrences of intra- or subretinal fluid due to choroidal neovascularization with or without drusen, and retinal pigment epithelial detachment.

Exclusion criteria: glaucoma, any optic neuropathy, diabetic retinopathy and maculopathy, severe media opacity, including advanced cataract, uveitis, amblyopia, degenerative myopia, retinitis pigmentosa, and vision problems secondary to cerebrovascular accidents.

Informed consent was obtained from all the patients before inclusion according to the recommendations of the Declaration of Helsinki, and after approval by the Ethical Committee of Lublin University.

Clinical assessment included age, gender, visual acuity, fundus fluorescein angiography and optical coherence tomography (Spectralis OCT by Heidelberg Engineering, Germany), history of medical conditions, presence of comorbidities (hypertension, cardiovascular disease, diabetes mellitus, thyroid problems) and the NEI VFQ-25 questionnaire. Patients underwent a complete ophthalmic examination.

The patient's place of residence was checked. The differentiation between village and city was made according to the list of Polish localities published in 2012 by Polish Ministry of Administration and Digitization.

The visual acuity was measured for far (at 5m) and reported as Logmar values, and near distance (at 30–40 cm) according to Snellen charts. The NEI VFQ-25 questionnaire consists of 25 questions which measure the subjective assessment of patient-reported answers about general health, general

vision, vision-specific mental health, vision-specific social functioning, vision-specific dependency, ocular pain, near and distant activities, role limitations, colour vision and peripheral vision. The overall composite score is calculated by taking the mean of all the NEI VFQ-25 subscales, excluding the general health subscale. [http://www.nei.nih.gov/resouces/visionfunction/manual_cm2000.pdf]

Statistic evaluation of the data was performed using Statistica 13.1. The continuous data were presented mainly as mean \pm SD, whereas categorical data as the number of patients or percentage values. A p-value of less than 0.05 was considered statistically significant. A p-value higher than 0.05 and lower than 0.1 was considered as a statistical tendency. Normal distribution was checked with the Shapiro-Wilk test. The Mann-Whitney test was used for non-normally distributed data. Quantitative variables with normal distribution were analysed with the paired Student t-test. Proportions were analysed by means of the chi-square test with Yates correction when needed.

RESULTS

The mean age of the study group was 76.3 \pm 12.3 years: males – 74.06 \pm 9.07, females – 76.49 \pm 8.02 years; average time of AMD – 4.24 \pm 4.1 years. Visual acuity among patients was 0.28 \pm 0.28 and near 0.76 \pm 0.79. 21.5% of patients reported comorbidities such as hypertension, cardiovascular disease, diabetes mellitus.

99 (68.75%) of the patients lived in a city, while 45 (31.25%) lived in a village. (Tab. 1).

Table 1. Demographics and clinical characteristics of the studied group.

Feature	Male	Female
Number	56 (38.8%)	88 (61.2%)
Age(years)	74.06 \pm 9.07	76.49 \pm 8.02
BCVA far	0.55 \pm 0.55	0.52 \pm 0.55
BCVA near	0.82 \pm 0.81	0.71 \pm 0.77
Time of AMD (years)	4.36 \pm 3.89	4.15 \pm 4.37
History of cardiovascular problem	12 (21.4%)	19 (21.6%)

Detailed analysis of the NEI-VGQ-25 questionnaire in the study group are shown in Table 2

Detailed analysis of the NEI-VGQ-25 questionnaire between women and men is showed in Table 2.

Table 2. NEI VFQ-25 results

NEI VFQ-25 questionnaire	Possible answers	Number of patients (%)	p Female vs. Male	P City vs. Village
1 In general, would you say your overall health is:	1. Excellent	2 (1.4)	0.9	<0.00001*
	2. Very Good	4 (2.8)		
	3. Good	50 (34.9)		
	4. Fair	54 (37.8)		
	5. Poor	33 (23.1)		
2 At the present time, would you say your eyesight using both eyes (with glasses or contact lenses, if you wear them) is excellent, good, fair, poor, or very p, or are you completely blind?	1. Excellent	0	0.67	<0.00001*
	2. Good	21 (14.7)		
	3. Fair	51 (35.7)		
	4. Poor	62 (43.3)		
	5. Very poor	8 (5.6)		
	6. Completely blind	1 (0.7)		

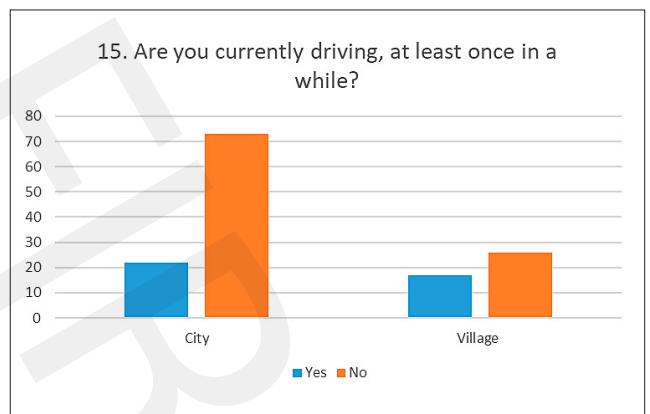
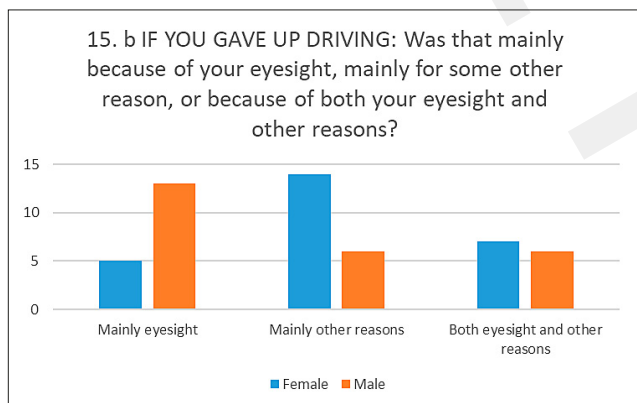
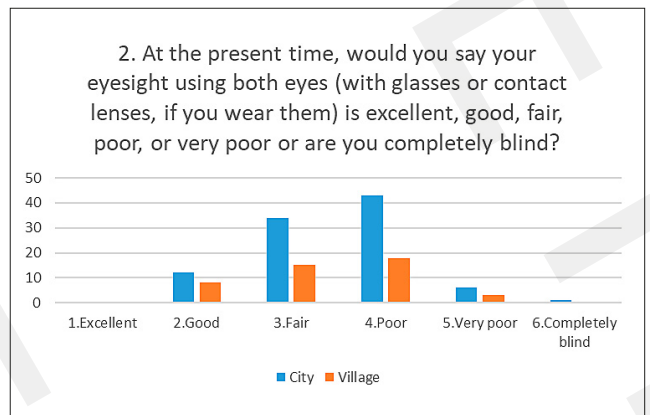
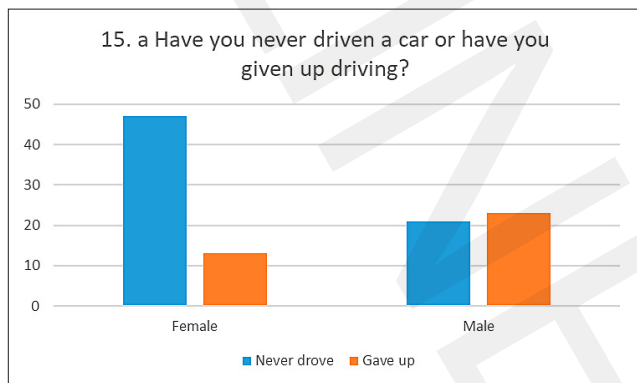
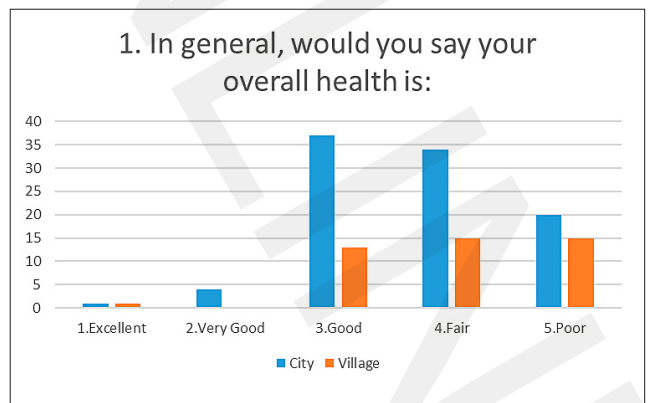
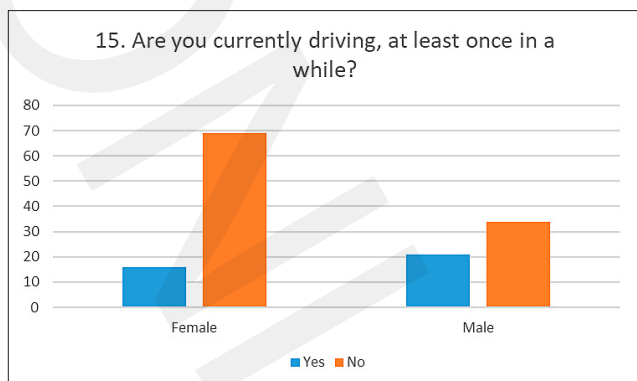
	NEI VFQ-25 questionnaire	Possible answers	Number of patients (%)	p Female vs. Male	P City vs. Village
3	How much of the time do you worry about your eyesight?	1. None of the time 2. A little of the time 3. Some of the time 4. Most of the time 5. All of the time	4 (2.8) 8 (5.6) 33 (23.1) 42 (29.4) 56 (39.1)	0.41	0.3108
4	How much pain or discomfort have you had in and around your eyes (for example, burning, itching, or aching)? Would you say it is:	1. None 2. Mild 3. Moderate 4. Severe 5. Very severe	39 (27.3) 39 (27.3) 56 (39.1) 8 (5.6) 1 (0.7)	0.0907[^]	0.934
5	How much difficulty do you have reading ordinary print in newspapers? Would you say you have:	1. No difficulty at all 2. A little difficulty 3. Moderate difficulty 4. Extreme difficulty 5. Stopped doing this because of your eyesight 6. Stopped doing this for other reasons, or not interested in doing this	12 (8.4) 18 (12.6) 47 (32.9) 25 (17.5) 38 (26.6) 3 (2.1)	0.744	0.0883[^]
6	How much difficulty do you have doing work or hobbies that require you to see well up close, such as cooking, sewing, fixing things around the house, or using hand tools? Would you say:	1. No difficulty at all 2. A little difficulty 3. Moderate difficulty 4. Extreme difficulty 5. Stopped doing this because of your eyesight 6. Stopped doing this for other reasons, or not interested in doing this	14 (9.8) 20 (13.9) 54 (37.8) 36 (25.2) 16 (11.2) 3 (2.1)	0.319	0.406
7	Because of your eyesight, how much difficulty do you have finding something on a cluttered shelf?	1. No difficulty at all 2. A little difficulty 3. Moderate difficulty 4. Extreme difficulty 5. Stopped doing this because of your eyesight 6. Stopped doing this for other reasons, or not interested in doing this	35 (24.5) 27 (18.9) 55 (38.5) 24 (16.8) 1 (0.7) 1 (0.7)	0.975	0.168
8	How much difficulty do you have reading street signs or the names of stores?	1. No difficulty at all 2. A little difficulty 3. Moderate difficulty 4. Extreme difficulty 5. Stopped doing this because of your eyesight 6. Stopped doing this for other reasons, or not interested in doing this	38 (26.6) 35 (24.5) 38 (26.6) 28 (19.6) 3 (2.1) 1 (0.7)	0.751	0.0823[^]
9	Because of your eyesight, how much difficulty do you have going down steps, stairs, or curbs in dim light or at night?	1. No difficulty at all 2. A little difficulty 3. Moderate difficulty 4. Extreme difficulty 5. Stopped doing this because of your eyesight 6. Stopped doing this for other reasons, or not interested in doing this	20 (13.9) 36 (25.2) 42 (29.4) 36 (25.2) 5 (3.5) 4 (2.8)	0.1977	0.3493
10	Because of your eyesight, how much difficulty do you have noticing objects off to the side while walking along?	1. No difficulty at all 2. A little difficulty 3. Moderate difficulty 4. Extreme difficulty 5. Stopped doing this because of your eyesight 6. Stopped doing this for other reasons, or not interested in doing this	39 (27.3) 36 (25.2) 44 (30.8) 20 (13.9) 2 (1.4) 2 (1.4)	0.5884	0.2286
11	Because of your eyesight, how much difficulty do you have seeing how people react to things you say?	1. No difficulty at all 2. A little difficulty 3. Moderate difficulty 4. Extreme difficulty 5. Stopped doing this because of your eyesight 6. Stopped doing this for other reasons, or not interested in doing this	56 (39.2) 31 (21.7) 35 (24.5) 17 (11.9) 1 (0.7) 3 (2.1)	0.2687	0.2310
12	Because of your eyesight, how much difficulty do you have selecting and matching your own clothes?	1. No difficulty at all 2. A little difficulty 3. Moderate difficulty 4. Extreme difficulty 5. Stopped doing this because of your eyesight 6. Stopped doing this for other reasons, or not interested in doing this	76 (53.1) 30 (20.9) 30 (20.9) 6 (4.2) 1 (0.7)	0.6251	0.231
13	Because of your eyesight, how much difficulty do you have visiting people in their homes, at parties, or in restaurants?	1. No difficulty at all 2. A little difficulty 3. Moderate difficulty 4. Extreme difficulty 5. Stopped doing this because of your eyesight 6. Stopped doing this for other reasons, or not interested in doing this	60 (41.9) 32 (22.4) 33 (23.1) 13 (9.1) 2 (1.4) 3 (2.1)	0.31	0.1383

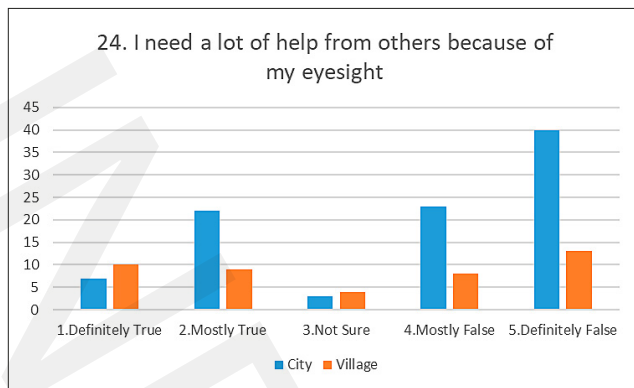
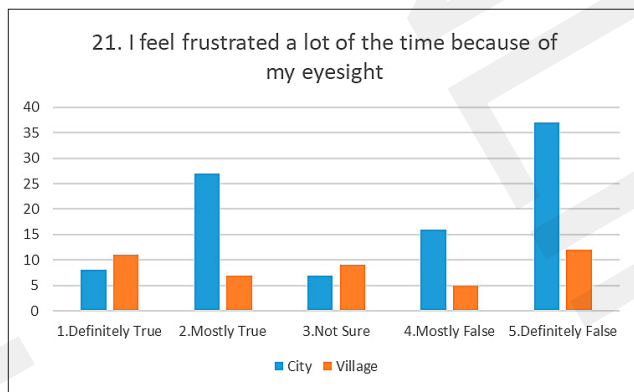
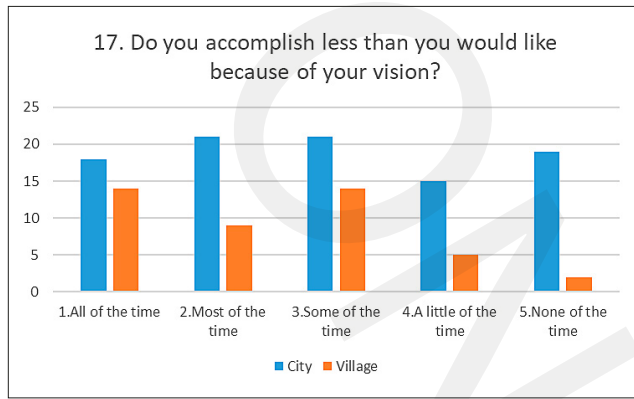
NEI VFQ-25 questionnaire	Possible answers	Number of patients (%)	p Female vs. Male	P City vs. Village
14 Because of your eyesight, how much difficulty do you have going out to see movies, plays, or sports events?	1. No difficulty at all	36 (25.2)	0.184	0.6625
	2. A little difficulty	25 (17.5)		
	3. Moderate difficulty	27 (18.9)		
	4. Extreme difficulty	16 (11.2)		
	5. Stopped doing this because of your eyesight	19 (13.3)		
	6. Stopped doing this for other reasons, or not interested in doing this	20 (14.0)		
15 Are you currently driving, at least once in a while?	1. Yes	40 (28.6)	0.0112*	0.0478*
	2. No	100 (71.4)		
15a IF NO: Have you never driven a car or have you given up driving?	1. Never driven	56 (59.6)	0.003*	0.0687^
	2. Gave up	38 (40.4)		
15b IF YOU GAVE UP DRIVING: Was that mainly because of your eyesight, mainly for some other reason, or because of both your eyesight and other reasons?	1. Mainly eyesight	18 (36.7)	0.03311*	0.8857
	2. Mainly other reasons	19 (38.8)		
	3. Both eyesight and other reasons	12 (24.5)		
15c IF CURRENTLY DRIVING: How much difficulty do you have during the daytime in familiar places? Would you say you have:	1. No difficulty at all	18 (50.0)	0.717	0.2658
	2. A little difficulty	5 (13.9)		
	3. Moderate difficulty	7 (19.4)		
	4. Extreme difficulty	5 (13.9)		
	5. Stopped doing this because of your eyesight	1 (2.8)		
	6. Stopped doing this for other reasons, or not interested in doing this	0		
16 How much difficulty do you have driving at night? Would you say you have:	1. No difficulty at all	7 (14.9)	0.722	0.5857
	2. A little difficulty	9 (19.1)		
	3. Moderate difficulty	7 (14.9)		
	4. Extreme difficulty	4 (8.5)		
	5. Stopped doing this because of your eyesight	13 (27.6)		
	6. Stopped doing this for other reasons, or not interested in doing this	7 (14.9)		
16a How much difficulty do you have driving in difficult conditions, such as in bad weather, during rush hour, on the freeway, or in city traffic? Would you say you have:	1. No difficulty at all	8 (17.4)	0.965	0.1047
	2. A little difficulty	10 (21.7)		
	3. Moderate difficulty	11 (23.9)		
	4. Extreme difficulty	1 (2.2)		
	5. Stopped doing this because of your eyesight	10 (21.7)		
	6. Stopped doing this for other reasons, or not interested in doing this	6 (13.0)		
17 Do you accomplish less than you would like because of your vision?	1. All of the time	31 (21.7)	0.4536	0.0632^
	2. Most of the time	28 (19.6)		
	3. Some of the time	38 (26.6)		
	4. Some of the time	22 (15.4)		
	5. None of the time	22 (15.4)		
18 Are you limited in how long you can work or do other activities because of your vision?	1. All of the time	23 (16.1)	0.2207	0.2541
	2. Most of the time	33 (23.1)		
	3. Some of the time	39 (27.3)		
	4. Some of the time	21 (14.7)		
	5. None of the time	26 (18.2)		
19 How much does pain or discomfort in or around your eyes, for example, burning, itching, or aching, keep you from doing what you'd like to be doing? Would you say:	1. All of the time	7 (4.9)	0.2107	0.7808
	2. Most of the time	25 (17.4)		
	3. Some of the time	34 (23.8)		
	4. A little of the time	34 (23.8)		
	5. None of the time	43 (30.1)		
20 I stay home most of the time because of my eyesight	1. Definitely True	19 (13.4)	0.9312	0.2052
	2. Mostly True	29 (20.4)		
	3. Not Sure	11 (7.7)		
	4. Mostly False	21 (14.8)		
	5. Definitely False	62 (43.7)		
21 I feel frustrated a lot of the time because of my eyesight	1. Definitely True	21 (14.8)	0.6630	0.0066*
	2. Mostly True	30 (21.1)		
	3. Not Sure	18 (12.7)		
	4. Mostly False	22 (15.5)		
	5. Definitely False	51 (35.9)		
22 I have much less control over what I do, because of my eyesight	1. Definitely True	23 (16.2)	0.5615	0.178
	2. Mostly True	45 (31.7)		
	3. Not Sure	16 (11.3)		
	4. Mostly False	20 (14.1)		
	5. Definitely False	38 (26.8)		
23 Because of my eyesight, I have to rely too much on what other people tell me	1. Definitely True	18 (12.7)	0.4180	0.4731
	2. Mostly True	31 (21.8)		
	3. Not Sure	10 (7.0)		
	4. Mostly False	27 (19.0)		
	5. Definitely False	56 (39.4)		

NEI VFQ-25 questionnaire	Possible answers	Number of patients (%)	p Female vs. Male	P City vs. Village
24 I need a lot of help from others because of my eyesight	1. Definitely True	17 (12.0)	0.6110	0.0451*
	2. Mostly True	29 (20.4)		
	3. Not Sure	8 (5.6)		
	4. Mostly False	34 (23.9)		
	5. Definitely False	54 (38.0)		
25 I worry about doing things that will embarrass myself or others because of my eyesight	1. Definitely True	9 (6.3)	0.4498	0.4508
	2. Mostly True	16 (11.3)		
	3. Not Sure	18 (12.7)		
	4. Mostly False	33 (23.2)		
	5. Definitely False	66 (46.5)		

*statistically significant; ^ statistical tendency

The questions to which answers obtained statistically significant results are presented below:





Among the NEI VFQ-25 questionnaire, NEI item # 4 showed a tendency that women complained about moderate and severe discomfort and pain more often than men ($p=0.09$). Most of the patients did not drive a car, even before the onset of the disease (females vs. males: 81% vs. 62.9%; $p=0.0112$). 62.8% of males gave up driving a car vs. 25.8% of females ($p=0.003$). The parameter regarding driving difficulties showed that 50% of males gave up driving because of their eyesight, whereas only 20.8% females decided to give up driving for the same reason ($p=0.033$).

In the current study, the population was divided into two groups according to their origin – village or city. There was a significant difference between the patients from the city and the village regarding general health condition and eyesight. A tendency was observed that respondents from the village complained more often about extreme difficulty with or even stopped reading newspapers, street signs or the names of stores, than patients from the city ($p=0.08$). Question

number 15 on the NEI-VFQ-25 demonstrated that 22.8% of the patients from the city were driving vs. 40.47% of patients from the village ($p=0.047$). In the group of patients who were not currently driving a car, 44.2% of city residents and only 25% of villagers had given up driving ($p=0.068$). A relevant difference was observed in the answers to question number 17: rural patients felt that they achieved much less because of their eyesight, while the patients from the city did not perceive such an association ($p=0.06$). City patients did not report any relationship between frustration and visual acuity or the need for help from others, in contrast to villagers (Tab. 2).

DISCUSSION

Central vision is severely affected secondary to geographic atrophy, disciform scar, or choroidal neovascularization in patients with advanced AMD. Previous studies have used the NEI VFQ-25 to confirm that AMD reduces Vision-Related Quality of Life (VRQoL), especially with activities related to central vision, such as reading, driving and facial recognition [8]. Therefore, the presented study investigated which personal factors are significantly impaired, and additionally how it correlates with environmental factors.

Exudative AMD is a chronic disease that rapidly reduces central vision. Geographical, population and socio-demographic differences may lead to variable results regarding the scores on depression, anxiety and quality-of-life scales. These results can also be influenced by factors relating to patients' expectations and habits. The study also attempted to assess patients' beliefs and fears relating to the disease, and the ways in which they react to the disease in different environmental circumstances.

The NEI-VFQ-25 test is among the most commonly used vision-specific QoL scales. It is well known and documented using this test for glaucoma patients and their visual impairments has great impact on VRQoL [9–11]. There are also few studies concerning AMD patients, e.g. Orr et al. found that NEI-VFQ-25 scores were positively correlated with good vision in AMD patients [2]. In the Age-Related Eye Disease Study, the researchers assessed NEI-VFQ-25 scores twice, with a four-year interval between assessments, and demonstrated that there was a significant association between NEI-VFQ-25 scores and the progression of AMD and vision loss [5]. However, none of the studies investigated the interaction between the place of residence and self-reported vision related quality of life.

The findings of the current study revealed that there are some differences between the subpopulations of patients with AMD living in rural and urban environments. It is interesting to note that difficulties in reading were more notably mentioned by rural patients. This suggests that prescribing low-vision devices in rural areas may be less common or probably that patients are not so well informed about such conveniences. Furthermore, rural patients felt that they achieved much less because of their vision loss in contrast to urban patients who did not perceive such an association. Presumably, this situation has something in common with previously mentioned reading difficulties and psychological distress caused by frustration or loss of independence.

Another problem that occurred to be significantly different in these two subgroups was driving a car. 44.2% of urban

patients declared having given up driving, in contrast to only 25% of the rural patients. This could be explained by the availability of public transport in the cities and much less so in rural areas. Thus, patients living in urban area who feel uncertain about their eyesight may choose other options than driving a car, whereas in the villages there are fewer such possibilities. This feature appears even stronger considering the fact that in the current study 40.47% of the rural patients were drivers, compared to 22.8% of patients in the urban area. This is probably the result of public transport diversification.

The third issue that is different in these two subpopulations of AMD patients is that rural patients felt that they achieved much less because of their visual impairment, while urban patients saw no such association.

None of these problems have been previously studied in any other country in relation to place of residence, it is therefore impossible to generalize that this is a global problem. In Poland, such discrepancies are also easily visible also in patients suffering from other diseases [12].

CONCLUSIONS

Rural patients in Poland experience a poorer level of vision-related function than urban patients concerning reading capability, and report a lower acceptance of the disease. More information and counseling should be given in clinical settings to help rural patients to adapt to their loss of central vision, and to match appropriate low-vision aids.

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