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ARTICLE

Real-life patient journey in neovascular age-related macular degeneration: a narrative medicine analysis in the Italian setting

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Abstract

Objectives To investigate the real-life experience of patients affected by neovascular age-related macular degeneration (nAMD), in the healthcare pathway for the management of the disease, using a "patient journey" and narrative method approach.

Methods The patient journey of subjects affected by nAMD was designed using a process-mapping methodology involving a team from 11 Italian centres. Subsequently, narratives were collected from nAMD patients and family members. The interviews were analyzed using the narrative medicine methodology.

Results Eleven specialized retina centres across Italy were involved and 205 narratives collected. In 29% of cases, patients underestimated their symptoms or attributed them to non-pathological causes, thus delaying the specialist consultation. The delay in accessing to care was due to a lack of awareness of this disease (50% of the participants didn't know what nAMD is) and to critical issues faced at first visit (long waiting lists, failed diagnosis, underestimation of the problem). Despite anti-VEGF therapies were perceived as effective in improving or stabilizing vision in 91% of narratives collected, 77% of patients still reduced or ceased daily activities such as reading and driving. Within the pathway of care there was not a multidisciplinary approach, and the patients were treated just by the ophthalmologist.

Conclusions nAMD may significantly affect the quality of life of affected patients, both from a functional and psychological point of view. The narrative medicine approach highlights some critical points in the healthcare journey of nAMD patients and represents a useful background in implementing patient management algorithms and pathways of care.

Background

Age-related macular degeneration (AMD) affects ~8.7% of people worldwide with disease progression and prevalence increasing parallel with aging, thus involving up to 17.6% among patients over 70 years old [1]. In the early phases of AMD, visual symptoms maybe absent or mild, and unnoticed by the patient. Conversely, the late phases of AMD (i.e., geographic atrophy and neovascular (n)AMD) are characterized by a significant central visual loss, causing a relevant limitation of daily life activities. In particular, the neovascular evolution of AMD, may show a rapid progression, and, if untreated, can lead to

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severe impairment of visual function within 2 years, with a bilateral involvement in ~50% within 5 years [2, 3]. The introduction of anti-VEGF intravitreal therapy has improved the visual prognosis for patients affected by nAMD, however, the early intervention and the patient's collaboration for a regular timing of the treatment are mandatory in order to obtain better results. The treatment requires multiple injections and a regular and frequent follow-up for a long period of time (years), with a significant burden for both the patient and his family, and for the healthcare system [4].

The term "patient journey" defines "the experience and the processes that patients undergo during the course of a disease and its treatment" [5]. In the context of modern healthcare, the patient journey embraces several composite steps that employ professional figures belonging to different healthcare settings and organizations [6]. The process-mapping is an approach already used by management, technical staff, and decision-makers for quality validation and it is a tool used to identify processes and change of actions, that allows to focus on critical issues and to work towards solutions [7]. Its output is generally in the form of flowchart that might also be integrated with information obtained from the real life of patients and their caregivers, including emotional and psychological aspects and read together as a single patient journey. In recent years, research started to focus on the real pathways of care of people affected by chronic diseases, using new methodological approaches besides evidence-based medicine (EBM), such as qualitative research, that allows researchers to obtain more detailed information about patients' quality of life (QoL) than quantitative surveys [8, 9]. Narrative medicine (NM) is a qualitative research approach that studies an individual's perspective when coping with distress caused by health issues [10]. It investigates the different aspects of a disease collecting narratives from patients, caregivers and healthcare professionals and analyzing each report through semantic coding [11]. While EBM typically starts from a specific clinical question (hypothesis) and collects data to challenge it (deductive process), qualitative studies (such as NM), inspired to Grounded theory, follow an inverse research process (inductive) by building a hypothesis from many collected observations [8, 9].

The aim of this study was to explore the experience of patients affected by nAMD in the healthcare pathway for the management of the disease, using a NM approach and the patient journey mapping process with a particular focus on analyzing the real sequence and development of the disease management, the quality and flaws of care and the patient's global perception of the journey.

Methods

The patient journey map

The first phase of the study was the patient journey mapping. It was developed by a consensus of Italian clinicians with expertise in treatment and management of nAMD, during a 1-day national workshop, held by the Istituto Studi Direzionali (ISTUD) Foundation. The faculty was composed of 11 ophthalmologists, divided in two working groups [7].

The mapping process focused on each step of the patient's pathway to consultation: the research of the correct healthcare facility, the process of obtaining the specialist consultations, the logistic to and from healthcare facilities, the people involved and their relationships with the patient. Each step was traced by the experts' group from the patients' perspective [7, 12]. The schematic representation of the mapping process is reported in Supplementary information [See Supplementary information 1–4].

Participants and recruitment for the NM phase

The second phase of the study took place in the healthcare context of the involved centres. Narratives from patients and caregivers family members were collected to outline their personal view of the patient journey. Its output was intentionally focused on the relational, emotional and affective perceptions of the participants. This second step of the study was performed as a larger and more informative patient survey, according to the NM approach. It took place from September 2014 to October 2015 in 11 highly specialized retina centres across Italy, authorized for intravitreal administration of anti-VEGF drugs. Participants, patients and family-member caregivers, were invited to be interviewed on a voluntary basis, at the retina centres, by qualified non-medically trained, administrative research staff, using the NM approach. Patients' inclusion criteria were as follows: age >50 years, diagnosis of neovascular AMD in at least one eye under anti-VEGF treatment. Exclusion criteria were as follows: any ocular or systemic disease other than AMD that could significantly affect visual function, or preclude AMD diagnosis (e.g., ocular media opacities), any clinical or demographical condition (e.g., educational level) limiting the correct comprehension and completion of the interview. Only patients' relatives were included in the study, as caregivers.

Data collection and narratives analysis

The entire oral testimony of each patient or caregiver was reported as narrative. The general plot was elaborated by a committee of two ophthalmologists and considered six domains: socio-demographic aspects; onset of the disease (first signs, emotions, impact on family and social sphere); pathway of care (access to care, diagnostic examinations, communication of the diagnosis, emotions and reactions to the disease); treatment (emotions and impact on everyday life); QoL (relationship with the disease, loss of independence at home, at work and during spare time); caregiving (support/care provided, activities and time involved). The interviewers were instructed on keeping an open attitude to the contents reported by the narrating person avoiding any previous knowledge on the disease to influence their question-making. The interview did not include strictly clinical questions (e.g., degree or severity of eye damage) and the study did not involve the consultation of patient clinical records. Narratives were analyzed by means of the QSR NVivo 10 software for the coding and interpretation of the collection of narratives [13, 14] aimed to evaluate common issues involving patients with nAMD from individual experiences of "care".

Results

The patient journey

The result of the output produced by the clinicians' consensus contributions was a complex path-plot starting from recognizing symptoms and ending with the disease treatment with intravitreal therapy. The patient journey mapping was subdivided in four charts: (1) From symptoms to access to care (2) Search for diagnosis (3) Medical examination and definition of the diagnosis (4) Anti-VEGF therapy [See Supplementary information 1–4]. These four phases in the pathway of care resulted to be quite similar to patients' and caregivers' narratives outcomes, as reported below.

Socio-demographic characteristics of nAMD patients and caregivers

The survey collected a total of 205 narratives: 163 from patients with nAMD, and 42 from caregivers. Demographic data of participants interviewed are summarized in Table 1.

In particular, among all patients, 20% were in the loading phase of intravitreal anti-VEGF treatment, while the remaining were in the post-loading phase, and the average number of intravitreal injections was 8 (from 1 to 30).

From symptoms to access to care

Patients' memory of the moment in which symptoms arose was narrated in a vivid way, as reported in Table 2.

According to the reports, the pathway of medical consultations was long and complex and symptoms were often not recognized at first instance (Table 3). However, when symptoms were present, they caused a significant reduction in patient's activities and relationships (e.g., reading, sewing, recognizing faces) causing patients' concern, often shared with their family (Table 2).

In 29% of cases, patients underestimated their symptoms or attributed them to non-pathological causes thus delaying the specialist consultation. The large majority of patients firstly referred to their local optometrist, pharmacist, or the general practitioner, possibly because they thought to be affected by a "minor" problem ("I thought I had cataract") and were substantially unaware of late AMD (Tables 2 and 3). Then, the delay in accessing to specific care was due to a lack of awareness of this disorder (50% of the participants didn't know what nAMD was) and also to critical issues faced during the first visits. The difficulty in communicating the symptoms to healthcare professionals may limit the mutual understanding and the patient's comfort in expressing himself (Table 3). Moreover, the patient narratives underlined the long waiting lists for having access to a specialized retina centre, but also an underestimation of the clinical problem, a failed diagnosis, a misdiagnosis and an inappropriate therapy (Table 4). Conversely, a positive connotation was related to the presentation of a clear plan of care (e.g., type of intervention, timing) and the perception that the ophthalmologist dedicated an adequate amount of time to explain the disease.

Table 1 Participants' demographic data.

Number of participants	nAMD patients $N = 163$	Caregivers $N = 42$
Male	62 (38%)	10 (23%)
Female	101 (62%)	32 (77%)
Age (years)		
Mean	76	59
SD	13.6	13.7
Range	46	65
Duration of AMD (months)		
Mean	18	–
SD	19	–
Range	110	–
Marital status		
Unmarried	5%	10%
Married	60%	68%
Divorced/widower	35%	22%
Relationship		
Parent	–	28 (67%)
Spouse/partner	–	8 (20%)
Brother/sister	–	3 (6%)
Other	–	3 (7%)

nAMD neovascular age-related macular degeneration, *N* number, *SD* standard deviation.

Table 2 Perception of symptoms.

Symptoms	Patients
Loss of vision	**25%**
"At the beginning of 2014, I noticed an unexpected loss of vision, so I went to a local ophthalmologist who immediately visited me, and told me that I had to do some tests; so I had them done"; "I noticed that I couldn't read anymore, I thought it was a moment but the next morning the problem was still there"; "One day I closed my right eye, and I noticed that the left one was completely blind"; "Suddenly I realized I could no longer see".	
Central spot	**18%**
"I went in front of the mirror, I covered my right eye and I could see well, then I covered my left eye and I saw a black spot"; "One day I noticed a shadow in my right eye"; "I had sight problems; at first I thought I had to change glasses, but then I was seeing a black hole and I went to the local ophthalmologist"; "I was riding to my sister's house, and when I went into her house I saw a black spot, as a persistent black sun".	
Crooked or wavy lines	**17%**
"While I was sewing I noticed the needle looked crooked. «I wonder how it happened!» I asked myself. I remember we were on the beach, doing odd jobs to spend time. I changed the needle, and I saw that even that one was crooked too, and all other ones as well"; "It was during a holiday, I remember I went to my son's house and I told him «Look, I see every line moving, swaying»; "I became aware of the problem as I noticed all the straight lines were starting to look crooked, like the street for example"; "The following day I was looking at a distant wall we could see from our house; at first I would see straight lines, and suddenly they would become crooked".	
I didn't notice anything – The Diagnostic Test	**12%**
"I was operated for a cataract on the right eye, and then, during a control examination, doctors found I had macular disease. It was the first time I was hearing that"; "I really didn't notice anything, I thought I had cataract, and I did have it indeed, it happened after my husband's death; it was sudden, or maybe I not and I just hadn't notice it before"; "I noticed it two years ago, I was always under medical control, I had cataract"; "My brother has macular degeneration, my cousin is blind. So I started to control my sight early, to make sure nothing was going wrong. In fact they found I also have macular degeneration and I started therapy early".	
Blurred vision	**10%**
"I noticed I couldn't see anymore from my right eye, it looked like I had a gauze in the centre of the eye, and I could hardly see"; "One day, while walking, I saw something that looked like fog. I thought I had to change my glasses. Later I understood it was not a matter of glasses, but my eyes"; "I went to get a pair of glasses to see better, and it seemed that the situation improved after that. Later, however, I started seeing everything foggy"; "While I was watching television, my left eye sight was blurry".	
Difficulty in reading	**8%**
"I noticed that I couldn't read well anymore"; "I read a lot, I also do crosswords. At a certain point, I couldn't read anymore"; "At first I started noticing I couldn't read anymore smaller letters, I couldn't read newspapers and books"; "I noticed that I could hardly read: I embroidered, had a good sight, but sewing and reading was starting to be very hard".	
Difficulty in seeing fine details	**5%**
"One evening I was sitting at my usual spot, but I couldn't see the [statue of the] Madonna. I got up, and the statue was there"; "Four or five years ago, while entering home, I was trying to insert keys in the hole, and he noticed that my attempts were useless, and I couldn't centre the keyhole"; "I noticed it while I was playing tennis, my passion: one evening I noticed that I couldn't see the ball"; "I noticed that, while I trying to hit a nail, I wasn't hitting on the nail, but on the wall".	
Not recognizing people	**3%**
"One day, while I was rubbing this eye, I noticed that the other eye was seeing people twisted and with grey outlines"; "I can see people, but not well"; "I noticed that something in my life had changed. I couldn't recognize no one anymore, and I started wondering"; "Three years ago I noticed that I couldn't recognize people greeting me".	
Diplopia	**2%**
"One day I told my daughter «I see double», and she answered «Are you joking?», and so we went to the hospital"; "About two weeks ago, I started seeing double, I went for a pair of glasses, but they sent me to the ophthalmologist"; "If I close one eye, I see normally, if I don't close it, I see double"; "I came to see all lines crooked, and in the motorway I saw all lines double".	

Table 3 Main issues encountered in the pathway of consultation.

	Patients
Explaining symptoms to healthcare professionals	
Asking help to healthcare professionals	**71%**
"I saw a visual distortion phenomenon, many years ago, maybe 20 years ago. I went to the hospital, where they visited me"; "Fortunately, I had already an appointment for a medical visit with my general practitioner. He asked me: «How are you?» and I answered that I was not fine at all…"	
No medical consultation, (problem underestimation or not recognized)	**29%**
"I saw lines of the fields, especially of tennis fields, (because I used to watch this sport on tv), that move a little. I didn't care to this."; "They gave antibiotics to me and all ended there, I didn't give importance enough to it."	
Medical consultations attended	
Ophthalmology	**79%**
"Come back home from the sea, we went to my ophthalmology, he said to me it was a macular degeneration." "I noticed that, when I had to pound nails on the wall, I didn't pound the nail but the wall next. I decided to go to our ophthalmologist and he suggested me this retina centre for further medical examinations".	
General practitioner	**21%**
"I needed to get closer to television because I wasn't able to understand anything. With my son, we went to our general practitioner, and then we went to an ophthalmology who visited me."; "I began to see also wavy lines. Through my general practitioner I arrived here, where they diagnosed me a macular degeneration."	
Optician	**8%**
"I went to an optician to change my glasses, but he had soon many doubts and suggested me to have a medical visit to an ophthalmology."; "It began with a detached retina in both eyes: I discovered it casually going to an optician."	
Pharmacist	**3%**
"I couldn't see anything, I hit against the wall of a pharmacy and then, at 19.30, I was in the emergency room."; "One morning, I woke up and I couldn't open my eye, I went in a pharmacy and they told me to go to the emergency room."	

Once referred to general ophthalmologist, often neither optical coherence tomography nor fluorescein angiography were prescribed. Among patients who had been prescribed those tests, most claimed they felt they had not been referred to these diagnostic and confirmatory tests urgently enough, with consequently delay in the beginning of treatment, and worsening of their visual function [15] (Table 4).

The study showed that patients visited on average at least two specialists before arriving to a centre specialized in the treatment of macular degeneration: 86% consulted more than one ophthalmologist before accessing a specialized centre.

Reaction to diagnosis of nAMD

Half of the patients did not recall any specific emotional reaction at the moment of diagnosis—most not understanding the meaning of the term *macular disease* used by the doctor—whereas 41% expressed negative feelings (anger, distrust, frustration), and 9% reacted manifesting a positive coping attitude (serenity, trust, hope). Approximately 18% initially attributed the visual problem to other causes such as cataract, eyeglasses, improper sun exposure, trauma, etc. Narratives highlighted patients' confusion and discomfort arising from the perception of doctor's lack of empathy and the use of direct inappropriate terms or expressions (e.g., "your eye is dead/gone"). Moreover, many patients declared not to be asked about family history of disease, nor were told about the risk of family history of nAMD. These difficulties in relationship with the medical personnel maybe frustrating for patients, preventing a free and successful communication. Thus, patients' decisions may not be fully personal, but partly delegated to their family members or doctors (e.g., "I didn't understand everything, so I said ok").

Treatment and perception of efficacy

Participants' descriptions of treatment most frequently included details on the number of intravitreal injections they received, and in particular to the emotional state linked to the first injection (Table 5). Negative feelings were linked to

Table 4 Main issues encountered after visiting the local ophthalmologist.

	Patients
Problems in booking a visit, and waiting lists	**29%**
"Overall, I was very upset. Everywhere I went had long waiting lists, but then they tell us that months make a difference."; "I called all the centres across my Region and I was continuously denied a visit and told that waiting times were long"; "I went for a visit and they referred me to … but waiting time was over a year"; "The secretary made me wait for over a month from the professor's return. I waited until he returned and then until my visit came. Meanwhile this spot that started out small grew to cover my entire pupil".	
Underestimation of the problem	**23%**
"When I noticed that the letters were falling under the line, I went to my eye doctor He didn't even request an angiography"; "They told me it was my impression. And that I still could use my other eyes. I had to be patient"; "And then the doctor said, «There isn't anything I can do for you at this point». I have the idea you underestimated the problem"; "I went to a visit at the public healthcare centre, they signalled me a green code, and say «You've got a cataract, and some dirt in the liquid, nothing serious», «But I saw a shady spot», «and what about now, can you see? », «If I keep my eyes half shut, I can», «No, there's nothing there, come back in six months and we'll check if it's a cataract». After six months, they say «The cataract isn't mature, come back in a year». I go back after a year and it was the same story over again".	
Inconclusive/missed diagnosis	**17%**
"I was puzzled, he didn't tell me anything specific"; "I believe that perhaps the doctor didn't want to tell me outright about the macular degeneration so she told me to come back and that for now everything appeared normal "She told me I had a weak eye"; "I could see a black spot through my right eye, but they were telling me everything was ok".	
Failure in the healthcare service	**11%**
"All the exams I had done were useless and had to be done all over again; it was like throwing them in the rubbish; they preferred do things over. I think there was a mistake somewhere"; "That doctor had a private practice, he told me his medication was better than the ones from the hospital; I still chose the hospital" "They probably made a mistake, a burn on my eye nerve"; "All the specialists should cooperate. One says "Yes, we'll do the injection, while the other says it's not going to change anything, and another colleague yet asks what we are still waiting for. Each time we're visited by a different doctor, so we don't establish any relationship."	
Wrong treatment	**9%**
"It's true that my first eye doctor was quite ignorant, the injections were already available, but he didn't prescribe them" "According to my ophthalmologists, there was no cure"; "I went to the hospital close to where I live and they said: "Why is it that you're showing up only now?!". And add "It's too late now, nothing to do about it" "I returned to my reference ophthalmologist who visited me. He said you have a dull eye, and told me they couldn't have done anything more than what had been done".	
Wrong diagnosis	**8%**
"I went to my ophthalmologist who submitted me to the tests needed, and suggested it was eye thrombosis. So first I started with eye drops but it wouldn't go away […]. My doctor wanted to suggest cortisone injections but I didn't agree and sought a second opinion. "My ophthalmologist said I had a cataract, but it was getting worse"; "He told me that it didn't seem to be anything wrong, it's probably a capillary that burst"; "When they mentioned macular disease, I thought it was an acerbation of my cataract. Some doctors mentioned eye nerve arthrosis! I smiled, I don't know anything about it, but I was wondering if such thing could even exist".	
Lack of diagnostic equipment	**3%**
"I booked a test at the hospital and discovered on the days of the test that the hospital did not even have the equipment to do the test. I cried and cried!"; "They prescribed all the tests needed and then they told me they were unable to go further and suggested I go to a better equipped hospital"; "I was told it was macular degeneration, but their equipment wasn't working and that they couldn't perform the angiography"; "I went to a private practitioner who then sent me here because I had to undergo some tests that he could not perform.	

an expectation of pain, as already noted in other studies [16, 17].

Of all narratives, 62% described their attitude/level of satisfaction towards treatment. Although 91% of patients stated to be stabilized or they felt improvement and benefit from treatment, 9% of patients was not satisfied, (Table 5) in agreement with other qualitative studies on AMD treatment [18, 19].

Narratives of patients who underwent different therapeutic options over the years, made comparison between

Table 5 Perception of intravitreal injections of anti-VEGF treatment.

	Patients
Emotional state linked to the first injection	
Fear and extreme anxiety	**30%**
"Firstly, they performed a laser and then they treated me with injections, because it was at the beginning. I was terrorized, I couldn't sleep the night before."; "Needle in the eye? There's nothing to do. I am always upset, I am not able to hide my fear, I am emotional, I usually have panic attacks and anxiety attacks."	
Discomfort	**20%**
"It bothered me and shocked me, the idea to do injections in the eye… but I do it." "Injections are those the bad things of the story. I suffer when I must lay down on the table to do injections. But, I do it."	
Concern	**15%**
"At my first injection, I was literary drawn."; "The idea of doing injections in my eye made me very afraid"	
Uneasiness or fainting	**10%**
"Two months ago, I came here for my first visit and today I do my first injection…if I don't escape before that!"; "When they said to me I had to do injections in my eye, I was dumbfounded."	
Treatments effectiveness	
Improvement and benefit	**51%**
"I must say that after the injections I feel benefits"; "Surely, after the injections I feel benefits, it's not traumatic for me doing them, while when I tell people I do injections in the eye they are always shocked"	
Stabilization	**31%**
"At the beginning, when they administered me …, I couldn't notice any benefit. It only stabilized my visual situation." "In 2014, they began to administer me …: I didn't notice any visual benefit, but I'm able to maintain the same visual situation doing many visits per year."	
Improvement markedly	**9%**
"In September, I was subjected to an injection and I had a moderate improvement" "I do nine injections totally of …, and it improves my vision a little. I could save what it was still be able to be saved"	
Not satisfaction	**9%**
"Actually, I must say that for the left eye, maybe, it was too late, thus that eye was too damaged for having any benefit." "[Before therapy] I saw bands, not plain…but I saw, at least! Now [after therapy], my vision is not improved, but worsening!"	

VEGF vascular endothelial growth factor.

previous treatments, and expressed their relief in changing to a treatment requiring fewer injections and visits to the eye clinic.

Impact on QoL

Although no clinical data on the stage of the disease were asked, patients' perceptions of their progressive vision impairment were collected (Table 6).

Among our patients, 77% declared to have reduced routine activities requiring optimal visual function—such as reading, sewing, driving—as well as other less demanding activities such as cooking. Among the routine activities within the household environment, inability to read was one of the most frequent problems [20]. The activity of watching television was maintained by most patients (59%) but with some difficulties, while 16% ceased this activity and 25% watch television normally. Some participants were concerned to become unable to watch television and to read as they were able previously. Twenty-six per cent ceased driving and 48% drove only at daytime, or for limited itineraries. The concerns and emotional implications related to the disease were expressed by two scenarios and coping strategies, outlined by the analysis of narratives. The first one was represented by the safe household environment, in which people would either handle their visual difficulties through basic strategies and compensative skills (positioning objects in easily reachable places), or surrender and withhold from activities and chores. The second scenario was represented by the environment outside home, which was

Table 6 Impact on quality of life.

	Patients
Reading	
Stop reading	**40%**
“I’m no longer able to read or write”; “Unfortunately I don’t read anymore”; “Surely I cannot read anymore. I read well the first lines, and then I start seeing them blurred, and I feel disoriented”; “I gave up reading, Books were my life!”	
I can hardly read	**44%**
“Now I’m hardly reading at all, but I react tackling”; “I don’t read fast as I used to, I have read slowly because of this distortion”; “I can’t read for more than ten minutes”; “My ability to read has decreased, and it’s a pity, reading has always been my passion; I’m hardly reading now”.	
I can read	**16%**
“I still read pretty well”; “I use glasses for reading”; “I read really well even at distance”; “I read, and I do crossword puzzles”; “I read and I write books”	
Driving	
I’ve stopped driving	**26%**
“Now I don’t have the driving licence, and this fact bothers me”; “I can’t drive anymore”; “For caution, I decided to not drive anymore”; “I was worried I couldn’t drive and watch television anymore, but my family didn’t understand”	
I drive less, or only in particular conditions	**48%**
“I drive, but hardly, especially by night”; “I drive, but I don’t certain grey days, if it’s raining, or by night, because I’m confused”; “It’s very difficult for me driving by night”; “I don’t drive to go far away”; “I don’t drive by night, and if I have to, I do it very carefully”.	
I drive	**15%**
“I drive both motorcycle and car without any problem”; “No problem, I drive”; “I drive, even by night”	
I drive, but I’m worried for the driving licence	**11%**
“As for driving, I do, because I still see pretty clearly with this eye. Maculopathy worries me, because now I should do again the driving licence and I don’t know if I reach the necessary 8/10”; “Sometimes I think that if the situation goes on this way, in 4-5 years I will not be able to drive”.	
Household environment	
Compensative strategies “At home I feel safer because I know where things are”; “Even if I can’t read very well, I still can cook and take care of my home”	
Surrender behaviour “ Now I also have difficulties in finding my things at home, so I had to find someone else to clean the house”	
Environment outside home	
“ I rarely go out because I don’t feel safe”; “My children hired a lady who accompany me for a walk everyday”	

perceived as more threatening, and requiring a higher degree of support and dependence on others to overcome obstacles and uncertainties. In fact, 26% of patients complained about loss of independence and frustration [21–23]. This emotional discomfort was expressed as concern, disorientation and sadness, however no experience of a psychological or specific support was reported (Table 6).

Caregivers and their experience with nAMD

In general, analyses of feedback from caregivers reflected the lack of knowledge about the disease (22%), as also found among the patient population. Among others, the attitude of the family member towards the diagnosis of nAMD triggered negative feelings (fear for severity of condition, compassion): 31% immediately associated diagnosis to the concept of blindness, 13% had a proactive attitude in seeking ways to treatment, 9% had regrets of not having taken actions sooner or were upset for the delay in receiving the diagnosis or the number of consultations needed to get a final diagnosis (Table 7). As regards the time dedicated to caregiving, 41% dedicated daily part-time or full-time assistance, while 59% dedicated 2 h or less to their relative with nAMD. However, 19% of total families turned to professional caregivers. Caregivers had been assisting their family member with AMD for a long period (more than

Table 7 Caregivers' perceptions.

	Subjects
Lack of knowledge	**22%**
"When they told us what was wrong I didn't understand very well, so I searched on internet"; "I didn't know this disease and I was a little worried for my mom".	
Negative feelings	**31%**
"I already suspected this diagnosis because my grandmother had it, but I hoped it was something else"; "The first thing I thought was that he could become blind and I was very worried"	
Proactive attitude	**13%**
"I understood that the disease was severe so I asked for beginning the treatment early"; "I was reassured because there was a treatment, so I thought there could be a solution"	
Regrets	**9%**
"I felt disappointed because we didn't try to have a visit earlier"; "The doctor said that the disease was already advanced, then I felt sorry for my dad because maybe it was too late"	

1 year) (84%), while 16% had been providing assistance for less than a year. The main activities provided by caregivers were reading documents, mail and books (40%), accompanying for a walk outdoors (40%), running errands (18%), housework (26%), cooking, personal hygiene and dressing (10%), spending time together and chatting (38%). The majority of patients were accompanied by caregivers (93%); considering that 26% of caregivers was employed, accompanying their family member to visits represented a social cost in terms of lost earning or vacation/permits.

Discussion

The significant impact of nAMD on patients' QoL, the relevant economic burden and the still limited availability of long term effective therapeutic options, have required, and still require, an important commitment from the ophthalmologic scientific community for the research in this field [1–4]. Although the clinical aspects of nAMD have been extensively studied, and still are, the patient's perceptions are often disregarded, while been the main purpose of the healthcare commitment. The first step of this study (experts' consensus) allowed a group of experienced Italian clinicians to focus and deeply understand the real healthcare pathway for nAMD not in terms of theoretical guidelines of their retina centres, but from the patient's perspective. The results of the consultation provided all the stakeholders involved in the management of nAMD, as patients, caregivers and professionals, with patient journey flowcharts to refer, in order to improve awareness on each step of the healthcare pathway in nAMD. Moreover, the NM method of analysis provided qualitative and emotional patient-guided information, generally not addressed by the majority of quantitative surveys on nAMD [20].

The most evident, widespread finding emerging from patients' narratives was a sense of discomfort secondary to the disease. In particular, this study highlighted a disagreement between some of the requirements expected in the flowchart produced by the consensus and the patients' experience. The patient journey map delineated the involvement of many professional figures in the early phases of the disease, even before the access to care, but according to the narratives, approximately half of the patients did not realize at that time what the medical term "AMD" referred to and what it involved, and gradually gained knowledge on the matter through personal experience. Although clinicians provided some guidance, narratives pointed out the patients' difficulty in expressing their symptoms, sorting the information received by the healthcare providers, understanding the medical terms used and thus conjugating their sensations with the explanations provided by the healthcare professionals. The terms and expressions used by ophthalmologists in explaining the diagnosis and prognosis to patients, showed to significantly influence the patient's perception of the disease, thus requiring particular attention from the physician. Moreover, at the moment of diagnosis, many patients declared that nothing had been asked about family history of disease, nor had been told about the risk of family history of nAMD, preventing to inform other family members who could potentially become affected by nAMD. This finding highlights two distinct aspects of the patient journey: the critical role in the patient–clinician communication, and the need for health literacy campaigns to improve the awareness of nAMD among target patient populations. In fact, among the critical points to address, emerged the understanding of the pathway of care, the route to get to the ophthalmologist, the correctness of the first steps of management, and thus the access to the referral centre. Therefore, strategies to improve the patient's journey should include the development of local protocols for an easy access for patients to the correct pathway of care but also the sensitization of the ophthalmology community about the necessity of a correct communication with patients for a better compliance and a reduced discomfort. In fact, the narratives underlined the frequent inability of patients to make decisions about their health, usually "delegating" their disease management and treatment choices completely to their physicians.

Another point of discrepancy between the patient journey flowcharts obtained from the experts consensus, and the patients' narratives regards the several comorbidities typically affecting AMD patients. While they were not considered in the patient journey mapping, according to narratives, many patients presented chronic diseases, or other non-visual disabilities, for which nAMD represented a further burden. Unfortunately, the lack of clinical data of participants did not allow the quantification of the impact of the different conditions in the patients' perceived QoL.

Regarding treatment, despite intravitreal anti-VEGF therapies were perceived as effective in improving or stabilizing vision in approximately all narratives collected, 77% of patients still reduced or ceased daily activities, with adverse effects on their QoL. The limitations caused by nAMD were experienced passively, with resignation. The narratives did not convey any attention to the future, nor to any adaptive strategy to perform a certain activity in a different manner. Active coping and the search for compensative strategies were limited in our population. Compared to other preventable disabilities or conditions, such as in the field of occupational health where there is a large development and diffusion of aids (orthopaedic, postural), visual aids (e.g., voice synthesis devices, audiobook, magnifying glasses) appear to be scarcely diffused and unknown among AMD patients.

Regarding intravitreal therapy, patients at their first experience (loading phase) expressed a shared initial fear for the pain due to the injection, which actually resulted less painful than expected and the fear reduced over time [24]. The reduced activities leading to discomfort and risk of depression, reported in the narratives, confirmed the positive correlation reported in the literature between visual impairment and decreased QoL [20, 21, 25, 26]. Despite patients often declared to feel a sense of sadness similar to depression, there was no specific professional figure assigned for psychological support, nor any course to train the person with AMD to the new condition of low vision. In fact, a focus on individual's sphere (illness) seems to be completely absent, without a noticeable coordination or multidisciplinary approach with other professionals such as psychologists, geriatricians, occupational therapists, counsellors, or rehabilitation therapists. As shown by previous studies, a holistic approach could improve the healthcare pathway both in terms of disease management (ophthalmologic problem) and emotional sphere, encouraging coping and determination in maintaining independence [26, 27].

This study has some limitations: first, the investigation is limited to the Italian context; second, all patients with nAMD were included regardless of specific clinical characteristics; although the clinical aspects of the disease could have provided a better patient characterization, the analysis of clinical data was not the aim of the study.

In conclusion, the present study analyzed some critical points in the healthcare journey of patients affected by nAMD giving useful insights to improve clinical practice and to implement patient management algorithms and pathways of care. It also showed the willingness of patients to share their experience and the value of narration in the approach to the disease.

Supplementary information is available at Eye's website.

Summary

What was known before

- Neovascular AMD is a rapidly progressive condition leading to central vision loss, causing a relevant burden in terms of management both for the patients and the healthcare system.
- Narrative medicine approach is useful to investigate the impact of a condition and for shaping future research and practice.

What this study adds

- Diagnosis of neovascular AMD results in significant and specific psychologic burden for the patient and limitation in daily life activities.
- The discrepancy between some of the requirements perceived by the physician for the management of the disease and the patients' experience may limit the efficacy of the healthcare pathway.

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Compliance with ethical standards

Conflict of interest MBP has participated in advisory boards of Novartis and Bayer; EM, MVarano, EP, GS, MC, AP, MVadalà, SD, LF, AF, MGM and LR declare no competing interests.

Ethical approval The study was submitted for approval to the Ethics Committee before beginning the collection of narratives. Before enrolment, all participants signed an informed consent, as foreseen by the Italian Law on *Privacy and safeguard of sensitive data*, with particular regard to: the aims of the project; the handling of personal data and of any reference to people, places, and treatments; the possibility to withdraw from the study at any time; the confidentiality in reporting the results. The entire study was performed in accordance with the Declaration of Helsinki.

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