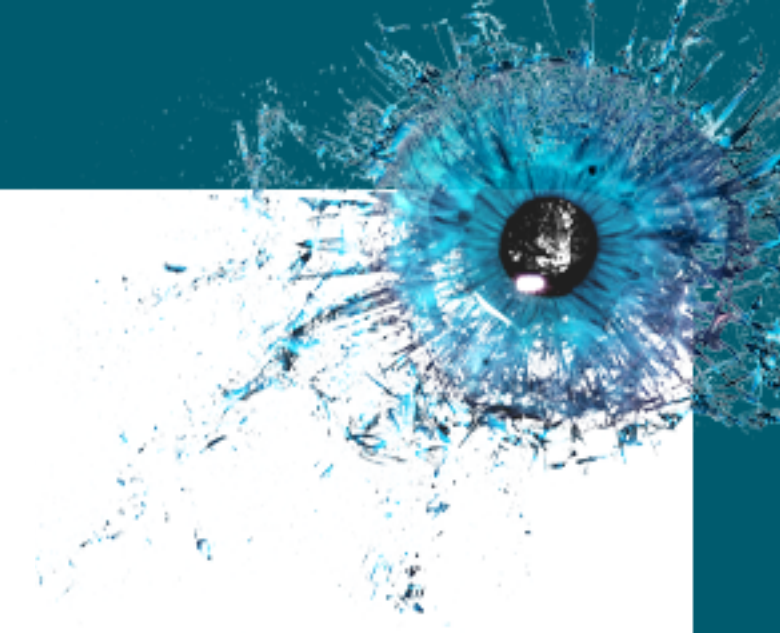


LA GESTIONE DEL PAZIENTE AFFETTO DA  
**DEGENERAZIONE MACULARE**  
SENILE ESSUDATIVA

**SABATO 19**  
**NOVEMBRE 2022**



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# **Il Patient Journey del paziente con DEGENERAZIONE MACULARE**



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

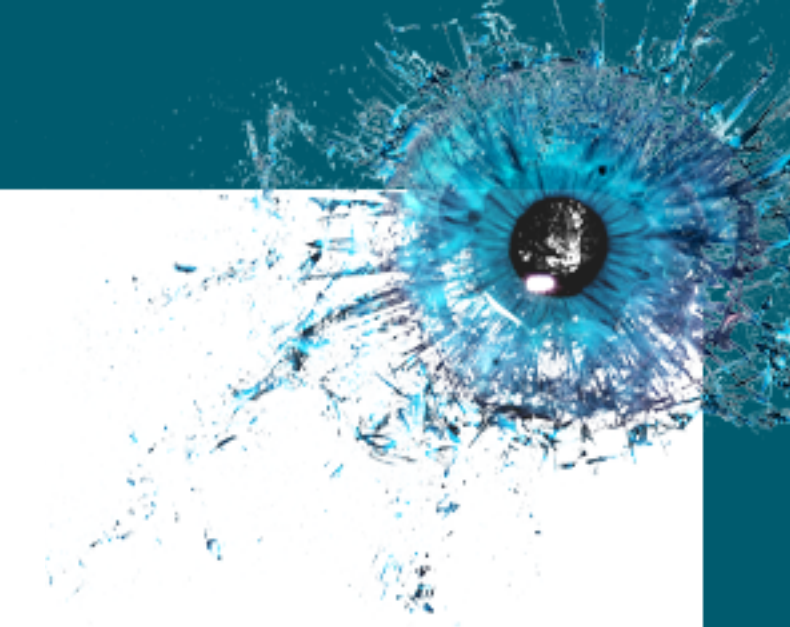
# Monica Varano

Edoardo Midena, Monica Varano, Elisabetta Pilotto, Giovanni Staurengi, Monica Camparini, Alfredo Pece, Maurizio Battaglia Parodi, Maria Vadalà, Simone Donati, Luisa Frizziero, Alessandra Fiorencis, Maria Giulia Marini, Luigi Reale- Eye march 2021

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.

### 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.



## Key point significativi

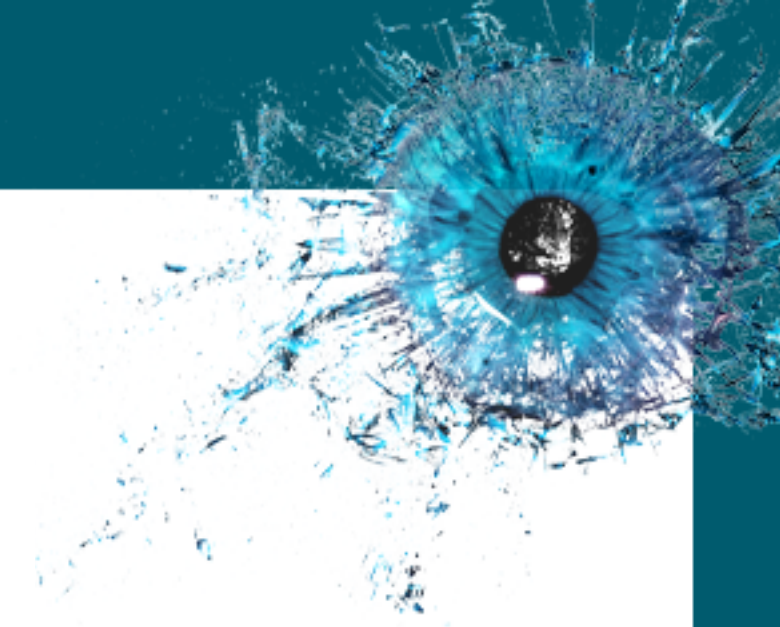
Eleven specialized retina centres across Italy were involved and 205 narratives collected.

In 29% of cases, patients underestimated their symptoms or attributed them to non-pathological causes, thus delaying the specialist consultation. ( Problema di comunicazione sulla malattia)

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). (Tempi di attesa e scarsa conoscenza )

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. (La cura rallenta ma in molti la qualità di vita peggiora)

Within the pathway of care there was not a multidisciplinary approach, and the patients were treated just by the ophthalmologist. (Manca un approccio multidisciplinare-dietologa,internista etc.)



# Il problema della diagnosi precoce

- I MMG sottovalutano spesso la malattia (Case di comunità possono offrire una risposta?)
- Quasi nessuna usa la griglia di Amsler (iniziative della regione per dogare ogni studio del MMG della griglia)
- Lamentano una grossa difficoltà ad inviare i pazienti per prima visita a meno che non sia una urgenza (sistema multilevel per diminuire le attese e nuovi modelli organizzativi)
- I tempi di attesa e trattamento sono lunghi a detrimento di un necessario trattamento precoce (spostare i trattamenti in ambulatori attrezzati e non solo nelle sale operatorie)



# Sostenibilità e ADM

- Fornire più centri delle attrezzature necessarie (OCT) per ridurre le attese
- Migliorare l'appropriatezza delle indicazioni
- Coinvolgere i Diabetologi per uno screening organizzativamente sostenibile
- Ricordarsi che non curare la gente comporta un sovraccarico su altre spese della pubblica amministrazione (INPS, assistenza sociale, etc.)
- La silver economy rappresenta una importante risorsa attuale e usura per il paese

