

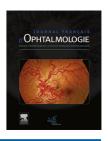
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### **EDITOR'S CHOICE**

# Neuro-ophthalmological conditions: Study of the clinical care pathway



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#### **KEYWORDS**

Neuroophthalmology; Clinical care pathway; Visual disability; Public health

#### Summary

Introduction. — Neuro-ophthalmologic conditions require specialized multidisciplinary management, both medical and surgical, for patients affected by visual loss due to nervous system disease. The primary goal of this study is to define the specificity of neuro-ophthalmology within the realm of visual health. The secondary goal is to review clinical care pathways by studying the organization of management, in terms of accessibility to care and personalization of the care pathway.

Patients and methods. — A field study was carried out from February to June 2015, within the ophthalmology service of the Pitié-Salpêtrière University Medical Center in Paris. A 30-minute interview with the patient before or after his or her neuro-ophthalmology consultation was performed, to describe the clinical care pathway. The medical records of interviewed patients were also analyzed.

Results. — Seventeen care pathways (10 women and 7 men) were reviewed. The mean age at appearance of visual involvement was 44.5 years ( $\pm$  8.4 years). If we exclude 3 patients over 66 years and retired, 35.71% were active, 35.71% were disabled, and 28.57% were on sick leave. Ten patients (58.82%) met the criteria for admission to long-term care. The first step had been carried out by local private practitioners. The first physician seen was the general medicine physician (59%), then the private ophthalmologist on an emergency basis (17%). On average, patients went through 8 steps during their care pathway (from 6 to 10 steps) and 14 medical

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departments were involved. The study showed collaboration with the other services of the University Hospital Department of Vision and Disabilities (notably with the Fondation Rothschild, the Quinze-Vingts National Ophthalmology Hospital, and the Fondation Sainte-Marie). In addition to rehabilitation services, health care professionals participating in the outpatient care of the patients included an orthoptist (11.7%), a psychologist (11.7%), and an optician specializing in low vision for visual aids. Finally, patient support groups, AFM-Téléthon (myasthenia) and the ARIBa association (visual disability) were solicited by 2 patients for their involvement. A disturbance in activities of daily living leading to disabilities with psychological repercussions was noted by a number of patients. The most frequent complaints involve mobility (29.41%) and reading (23.52%). In total, 77% of patients state that their well-being has been affected, and they are disturbed by the progression of their disease.

Discussion and conclusions. — The review of the clinical care pathway of patients affected by neuro-ophthalmological conditions shows that these pathologies are, on the one hand, often poorly understood, and on the other hand complex, leading to an often significant number of steps for the patient. This also emphasizes the necessity of a care network, specialized and structured to improve the efficiency of this management. Finally, these results demonstrate the existence of a very frequent disability, which may affect all aspects of the patients' lives, highlighting the importance of rehabilitation services and individuals participating in the follow-up of these patients beyond their acute care.

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#### Introduction

Neuro-ophthalmic conditions remain today relatively less well-known than other forms of visual conditions. They require multidisciplinary management with an emphasis on neuro-ophthalmology. This discipline medically and surgically addresses patients with a visual condition related to a nervous system disease. Putting in place the necessary competencies and logistics insures the patient the appropriate care. For patients with visual involvement of cerebral origin, the clinical care pathway most often takes place within a hospital. This observation begs the question of the reasons for this exclusivity and the specifics of management of this category of patients.

The primary objective of this study is to define the specifics of neuro-ophthalmology within the realm of eye care. The secondary objective is to reconstruct the patient's clinical care pathway by studying the organization of clinical care in terms of accessibility to care and personalization of the care pathway. This study will approach the question of management of the person faced with the repercussions of visual problems on his or her quality of life. A field study was undertaken within the ophthalmology service of la Pitié-Salpêtrière in Paris.

An assessment of the location of service in the management of the patient was made by reconstructing his or her clinical care pathway [1,2,3]. This consists of a number of steps through which the patient must go, depending on the pathway determined by his or her disease and specific situation, from his or her arrival to the hospital, through various services and professionals in charge of his or her management, and his or her care throughout the course of the disease. The goal is to preserve a global and coordinated approach to the patient, the implementation of which has three objectives: insure timely management at the various stages so as to optimize the plan for the benefit of the patient, contribute to the economic efficiency of the

healthcare system, with traceability of the care pathway in accordance with the patient's actual needs, and coordinate the actions of various providers involved in the patient's management, in a formalized manner, in such a way that they can be identified and evaluated at each step of the patient's management.

The question of organization of care is posed even with the hospital, due to the hyper-specialization of teams and medical-technical platforms. Its proper functioning depends not only on communication between professionals about the patient's health status, examinations performed, diagnoses considered and treatments in progress, but also on continuity and quality of care. The goal of the hospital is to associate and mobilize the providers and the competencies of their local colleagues and to preserve a global and coordinated approach to the patient. Global management also requires close collaboration between neuro-ophthalmologists, orthoptists, neurologists, neurosurgeons and neuroradiologists.

The ophthalmology service of la Pitié-Salpêtrière University Hospital is affiliated with the Neurosensory Surgery Division and is part of the "Vision and Disability" University Hospital Department (UHD). It is also a referral center for rare diseases in ophthalmology. The Vision and Disability UHD was established in June 2012. It is a unique entity in Île de France, combining various services from several hospitals, managing vision and visual disabilities. It includes care organizations (emergency or conventional) as well as research organizations, so as to offer patients the most complete possible management not only of their visual pathology but also of the resulting visual disability. These missions concern prevention, screening, diagnostic and therapeutic management of visual conditions, but also recovery and specific rehabilitation for the resulting functional consequences. Within the UHD, a task force dedicated to neuroophthalmology allows for structured management of these patients. The members of the services of the Fondation

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