Discussion

Communicative strategies for improving compliance in long-term management of optic nerve disease

Nataliia Moyseyenko

Ivano-Frankivsk National Medical University, Ivano-Frankivsk (Ukraine)

Комунікативні стратегії забезпечення комплаєнсу при довготривалому менеджменті захворювань зорового нерва

Наталія Мойсеєнко

Івано-Франківський національний медичний університет, Івано-Франківськ (Україна)

Abstract

Introduction. *Effective physician-patient interaction is a critical factor in the management of chronic disorders. In neuroophthalmology, a lack of structured communication and patient's psychoemotional catastrophization caused by the fear of the loss of sight can result in poor treatment compliance and treatment dropout.*

Purpose. *First, to demonstrate our clinical experience in the use of a combination of communication strategies based on the adapted SPIKES protocol, for improved long-term treatment compliance in patients with severe optic nerve pathology, and, second, to justify the significance of these strategies as an essential component of the rehabilitation roadmap. A six-step algorithm of the SPIKES protocol for communicating the diagnosis and prognosis adapted for a linguistic "low marginality" concept (with treatment success defined as the preservation of residual functions) was introduced onto clinical practice in combination with daily "Vision diary" keeping by patients.*

Results. *The use of a communication rehabilitation model developed enabled achieving a mean personal adherence rate of 88.4% at 6 months.*

Conclusion. *The SPIKES protocol integrated with the "Vision diary" is an independent and justified component of rehabilitation programs. This integration transforms the paradigm of doctor-patient interaction, restoring a patient's sense of control over the disease and maximizing therapy adherence.*

Keywords: *optic nerve, compliance, the SPIKES protocol, vision diary, neuroophthalmology, healthcare communication.*

Резюме

Вступ. *Ефективна взаємодія між лікарем та пацієнтом є критичним фактором у менеджменті хронічних захворювань. У нейроофтальмології брак структурованої комунікації та психоемоційна катастрофізація пацієнтів через страх втрати зору призводять до падіння комплаєнсу та самовільної відмови від лікування.*

Мета дослідження *– продемонструвати власний клінічний досвід застосування комплексу комунікативних стратегій на основі адаптованого протоколу SPIKES для забезпечення та підвищення довготривалого комплаєнсу у пацієнтів із тяжкою патологією зорового нерва, а також обґрунтувати їхнє значення як невід'ємного компонента реабілітаційного маршруту.*

Матеріали та методи. *Проведено комплексне обстеження та динамічний моніторинг 6 пацієнтів із тяжкою офтальмопатологією (зокрема, наслідками черепно-мозкових травм, мінно-вибухових загороджень, ішемічними*

DOI: https://doi.org/10.31288/Ukr.j.ophthalmol.202657782

UDC:617.731-009.11-08-039.73:614.253.8

Corresponding author: Natalya M. Moyseyenko, Dr Sc (Med) and Ass. Prof. at the Department of Ophthalmology, Ivano-Frankivsk National Medical University, 2 Halytska Street, Ivano-Frankivsk, 76000, Ukraine. E-mail: natalymoyseenko@gmail.com

Received 2026-05-17

Accepted 2026-10-08

Cite this article as: Moyseyenko N.M. Communicative strategies for improving compliance in long-term management of optic nerve disease. Ukr. j. ophthalmol. 2026;5:77-82.

This is an open access article under the Creative Commons Attribution 4.0 International (CC BY 4.0) license

© The Author, 2026

інфарктами та прогресуючими атрофіями зорового нерва). У клінічну практику було впроваджено 6-етапний алгоритм повідомлення діагнозу та прогнозу SPIKES, адаптований під концепцію лінгвістичної «низької маржинальності» (де збереження функцій є успіхом), у поєднанні з щоденним веденням пацієнтами контрастного «Щоденника зору».

Результати. *Застосування розробленої комунікативно-реабілітаційної моделі дозволило досягти рівня комплаєнсу 88,4% через 6 місяців спостереження.*

Висновки. *Інтеграція протоколу SPIKES та «Щоденника зору» є самостійним обґрунтованим компонентом реабілітаційних програм. Вона трансформує парадигму взаємодії, повертає пацієнту відчуття контролю над хворобою та максимізує прихильність до терапії. Перспективою є цифровізація щоденника у мобільний додаток із голосовим інтерфейсом.*

Ключові слова: *зоровий нерв, комплаєнс, протокол SPIKES, щоденник зору, нейроофтальмологія, медична комунікація.*

Introduction

Systemic deficiency of effective communication in modern clinical practice

Despite rapid technological progress in healthcare, poor physician-patient interaction remains a major hidden cause of therapeutic failures. Medical communication gaps have been reported: clinicians often overestimate the quality of information provided by them, and 40–80% of medical information provided by healthcare practitioners is forgotten immediately or interpreted incorrectly [1, 2].

For a long time, communication skills were viewed as a secondary, purely service element of medical practice. Today, however, the international scientific community considers the doctor-patient interaction as an independent clinical interaction. Studies have demonstrated a significant impact of effective communication on treatment outcomes and patient adherence to treatment [3, 4]. It is for this reason that leading healthcare institutions (e.g., the World Health Organization [5]) focus their efforts on introducing standardized tools capable of transforming a passive and frightened patient into an active participant in their care.

Specifics of physician-patient communication barriers in ophthalmological practice

Ophthalmological professionals and patients experience specific psychological challenges. Vision is a dominant perceptual ability in humans, and provides the human brain with 80–90% of information about the surrounding world. Progressive visual loss can cause severe distress and perception of low social status, which can be comparable in psychoemotional load to chronic stress in terminal somatic conditions [6].

Another communication barrier is digital and instrumental egocentrism of current ophthalmology. Complex imaging techniques such as optical coherence tomography (OCT) or automated perimetry often make the physician shift the focus of his or her attention to the analysis of graphs and morphometric indices (RNFL, GCC, MD), whereas the patient is left alone with his or her fear of unknown terms. The absence of patient-friendly explanations of the results of imaging examinations triggers doctor shopping, a phenomenon that entails patients seeing multiple clinicians [6]. Such fragmentation of care disrupts the continuity of long-term management of chronic conditions.

A phenomenon of marginal clinical effect in optic nerve disorders

Thresholds of compliance in neuroophthalmology are determined by the pathophysiological features of the optic nerve. Unlike cataract surgery which provides fast outcomes, treatment of optic neuropathies (severe neuritis, ischemic neuropathy, progressive optic atrophy) is characterized by marginal clinical improvement.

A marginal improvement in visual acuity (e.g., gaining several ETDRS letters) or stabilization of visual fields in a patient with optic neuropathy requires consistent efforts over a long period of time in real clinical conditions. In such cases, therapeutic, neuroprotective and rehabilitation interventions should be continued for at least 6 months, since neurodegenerative processes can persist for months [7]. Moreover, in cases with phthisis bulbi or ischemic infarction of the optic disc, anatomic fiber regeneration is impossible, and therapeutic success is defined as the preservation of residual functions and prevention of further damage from the disease. The patient may perceive this outcome as “poor”. A cognitive pitfall develops: unrealistic expectations for cure are followed by disappointment, loss of treatment compliance, leading to inevitable total loss of visual functions. It has been demonstrated that patients who had failed to develop proper cognitive understanding of the treatment process tended to lose compliance as early as first months of treatment [8].

Justification for the selection of the Setting, Perception, Invitation, Knowledge, Emotions, and Strategy/Summary (SPIKES) protocol

The review of current academic sources has confirmed that implementing structured technologies is the only way to overcome healthcare communication gaps. Large-scale studies, particularly, Glaucoma Adherence and Persistence Study (GAPS), demonstrated that poor adherence of patients with progressive optic neuropathy to prescribed medications is often associated not with financial considerations, but with a failure to understand clearly the pathogenesis and the endpoint of treatment [9].

SPIKES (Setting, Perception, Invitation, Knowledge, Emotions, and Strategy and Summery) is a skills-based, best-practices approach to giving bad news. Recent studies have reported on the efficacy of the SPIKES protocol in chronic sight-threatening disorders [10, 11]. Adaptation of

step P (Perception) establishes the patient's baseline perception of the situation and helps determining if the patient has unrealistic expectations of treatment. Additionally, step S (Strategy/Summary) shifts the focus of a patient's attention from potential disability to a particular step-by-step management plan.

The integration of this ethical protocol into the clinical admission process with its support by an at-home physical rehabilitation technique, a "Vision diary" developed by the author, enables normalizing the treatment timeframe in the patient's mind and transforming the marginality of the effect into the expected and well-controlled stability.

The purpose of this study was (1) to demonstrate our clinical experience in the use of a combination of communication strategies involving the adapted SPIKES protocol and a "Vision diary" developed by the author, for an improved long-term compliance to treatment in patients with severe optic nerve pathology, and (2) justify this integrated approach as a component of the rehabilitation roadmap.

Material and Methods

This study was designed as retrospective cases series from the author's neuroophthalmological practice. It is a conceptual study focused exclusively on the specifics of communicative techniques, adaptation of SPIKES steps, and implementation of the "Vision diary" (Fig. 1).

Characteristics of the clinical sample and inclusion criteria

The present study reviews the long-term management of six patients with severe optic nerve pathology who were examined and treated at the Department of Ophthalmology, Ivano-Frankivsk National Medical University. These included two patients with ischemic optic neuropathy, two patients with traumatic optic nerve injury, and two patients with compressive descending optic atrophy.

Inclusion criteria were (a) a verified diagnosis of optic nerve lesion with a high risk of irreversible visual function loss or low potential for complete visual recovery, (b) at least a 6-month history of the disease or a plan for disease monitoring for at least 6 months, and (c) subacute or chronic progressive visual function loss with marked visual field defects (scotomata, hemianopsia, and/or tubular visual field defects).

Methodology for implementing the SPIKES protocol

Compliance control was implemented through the compulsory use of adapted six-step SPIKES protocol:

S (Setting up the interview): setting up a therapeutic space: arranging for some privacy; having some close relatives of the patient's choice present, sitting down, making a connection with the patient and managing time constraints;

P (Assessing the patient's Perception): establishing the patient's perception of the situation ("What have you been told about the condition of your eye so far?") for determining if the patient is engaging in any variation of illness denial (e.g., wishful thinking);

I (Obtaining the patient's Invitation): determining what details the patient wants to know about examination (OCT, perimetry) results;

K (Giving Knowledge and information to the patient): moving away from just the statement of the loss of function to "in a nutshell" explanation of neuropathy and the concept of "low marginality". The wording "We have to deal with optic nerve fiber damage, working hard to preserve the present level of visual function" was used instead of toxic clichés.

E (Addressing the patients Emotions with emphatic responses): normalizing a patient's fear of blindness and using a patient partnership protocol and metaphors of collaboration to address the patient's distress, and

S (Strategy and Summary): developing a step-by-step rehabilitation roadmap and providing the patient with the "Vision diary".

"Vision diary", a technique for implementing physical rehabilitation

Each patient was provided with a structured "Vision diary" developed by the author. Given the impairment of visual functions in patients, the diary featured a customized ergonomic design with high-contrast 16- to 18-point font letters printed in black on a white or yellow background. It consisted of three parts.

Part A (Functional self-monitoring): a daily subjective assessment of residual vision for brightness and contrast and recording scotoma borders of density using a simplified grid.

Part B (Implementing physical rehabilitation): recording the results of daily exercises for optimal use of residual vision (fixating the gaze with preserved retinal regions and visual-motor coordination training).

Part C (Controlling treatment adherence): a medication list to keep track of all the prescription (neuroprotective or systemic) medications the patient takes each day.

Methods for assessing strategy efficacy

Strategy efficacy was assessed at 3 months and 6 months using the following criteria: adherence rate (based on medication list tracking and adherence to appointment schedule) and changes in Hospital Anxiety and Depression Scale (HADS) anxiety scores.

Results

Clinical deconstruction of patient's illusions and adaptation of SPIKES steps in neuroophhthalmology

The model developed for implementing each communication step is presented below using representative cases from our practice.

Step S (Setting up a therapeutic space)

Example case: A 30-year-old male patient with mine blast injury sequelae and bilateral descending optic atrophy (visual acuity of 0.01 with a tubular visual field small-

er than 5º). The talk was held in a quiet room, with the doctor saying: "Now I am sitting opposite you, with your wife sitting next to us. We will discuss the results of your examination in detail". The involvement of the wife contributed to subsequent medication adherence.

Step P (Perception): Deconstruction of patient's illusions

Example case: A 46-year-old female patient with acute papillitis associated with disseminated toxoplasmic granulomatous chorioretinitis. When asked by the doctor about her understanding of her condition, she responded: "I believe that now I will be treated for five days with eye drops, and fogging in my eyes will disappear entirely". The identification of this cognitive pitfall enabled correcting patient expectations before durable systemic therapy was prescribed.

Step I (Invitation): Normalizing the amount of information

Example case: A 43-year-old male patient with glaucomatous neuropathy in the presence of normalized intraocular pressure (IOP) and progressive visual field defects. The doctor said: "We have detailed OCT optic nerve scans. Would you like me to show you particular areas of optic nerve thinning on OCT or would you like us to move straight to the treatment plan?" The patient opted for reviewing the graphs showing the areas of optic nerve thinning, which increased his involvement in the process.

Step K (Knowledge): A language concept of low marginality

Example case: A 63-year-old male patient with ischemic neuropathy (ischemic infarction of the optic disc) and visual acuity OD as low as 0.01. The doctor used the SPIKES model ("The vessel supplying the optic nerve was severely injured, either burst or became blocked. Although we cannot restore the dead nerve fibers, there is a region of depressed cells surrounding them. We have to work hard to preserve you present level of visual acuity, and no visual worsening during the following six months will be deemed to be a success") instead of a destructive cliché ("The optic nerve has died and vision will not be restored").

Step E (Empathy): Empathy through partnership

Example case: A 58-year-old female patient with high degenerative myopia and partial optic nerve atrophy burst into tears during the appointment. The doctor used the mirroring technique: "I can see that listening about atrophy is difficult and frightening for you. This is a natural response. But you are not alone in this. We will develop a step-by-step treatment plan, and your involvement in this plan is crucial".

Step S (Strategy & Summary): Delegating subjectivity through the "Vision diary"

Example case: A 19-year-old male patient with optic nerve injury, diplopia and ptosis secondary to gunshot wound to the head was provided with a "Vision diary" to make records of his daily visual-motor coordination and diplopia monitoring tasks.

Results of introducing a "Vision diary"

The introduction of a structured self-monitoring diary allowed us to turn a long-term stabilization period into a visualized and controlled process. The following qualitative changes were noted based on the results of six-month monitoring of the six patients:

Overcoming medical futility: Daily recording of stable object contours in free-text fields of the diary (Fig. 1) allowed the patients to visually confirm no further deterioration in vision. By the end of month 6, five of the six patients exhibited a reduction in HADS anxiety score, with a shift from subclinical anxiety to a normal score range of 5 to 7, and

Maintaining compliance for a long period of time: Five patients exhibited an indivisual adherence rate exceeding 92% (with diary records for more than 165 of the total 180 days and with no interruptions in therapy). Only a patient with compressive optic atrophy had a lower adherence rate with a 14-day interruption in records, which was promptly detected during scheduled monitoring and corrected through a repeated communication session of the E (Empathy) step of the SPIKES protocol.

Discussion

Adapting international experience with the use of the SPIKES protocol in ophthalmological

Although the SPIKES protocol was initially developed to help clinicians respond to patients with cancer and their relatives, the distress induced by the threat of sight loss is profoundly existential and its impact on the quality of life is similar to that of a severe somatic disease [6, 10].

The available literature is scant on the introduction of the SPIKES protocol in the long-term management of optic nerve disease. Most publications are related to the general issues of communicating the diagnosis to the patient [10] or assessing ophthalmologists' skills without reference to neurodegenerative disorders [11]. Our approach demonstrates that, in optic neuropathy, it is critical not only to detect patient's destructive illusions early (step P), but also to transform the linguistic perception of treatment outcomes (step K) and to move to active partnership (step S). A lack of structured communication triggers a destructive phenomenon of doctor shopping [6], disrupting the continuity of long-term management of chronic conditions.

Features of the formation of patient adherence with treatment

The novelty of the proposed approach lies in the synergetic integration of the SPIKES protocol with a "Vision diary" developed by the author (Fig. 1), a practical tool for at-home rehabilitation. The approach was found to be helpful in overcoming the communication gap described in the literature in which a large portion of the recommendations provided by healthcare practitioners is forgotten immediately or interpreted incorrectly [1, 2].

In the presence of a conventional communication model, the rate of adherence to treatment for chronic eye disease at 6 months is usually as low 40–55%, with a high treatment dropout rate during the first treatment months [1, 10, 11]. With the integration of the SPIKES protocol with the "Vision diary", most patients in this case series exhibited a high personal adherence rate (with diary records for more than 92% of days), and therapy interruptions initiated by the patient were exceptionally rare.

Declaring the stabilization of visual function or maintenance of visual fields over six months a clinical success (but not a failure) dispelled destructive expectations. Additionally, making diary records on a regular basis, with the patient recording the contours of the control object in special fields of the diary, was helpful for visualizing the stability of the process. In this study, step S of the protocol was completed by providing an ergonomically adapted physical guide, which completely offset the patient's memory deficit and excluded the risk of loss of medical instructions.

Limitations of the study

Since this case series is a preliminary observational study, with the number of cases (n = 6) being too small to allow for a full-fledged statistical analysis, a representative multicenter study is warranted for pathophysiological and psychosomatic justification of the method.

Conclusion

The SPIKES protocol integrated with the "Vision diary" is an independent component of rehabilitation programs. This integration transforms the paradigm of provider-patient interaction, restoring a patient's sense of control over the disease and maximizing therapy adherence. Future studies will be aimed at applying the method in neuroprotective treatment and physical rehabilitation.

Author Contributions

The author confirms sole responsibility for the concept and design of the study, data collection, analysis and interpretation of results, and preparation of the manuscript.

Funding Sources

The authors declare that no funds, grants or other support was received during the preparation of the manuscript. The sponsor or funding organization had no role in the design or conduct of this research.

Conflict of interest

The authors state that they have no conflict of interest that could influence their view on the subject matter or materials described and discussed in this manuscript.

Data Availability Statement

All data generated or analyzed during this study are included in this published article (within figures and text).

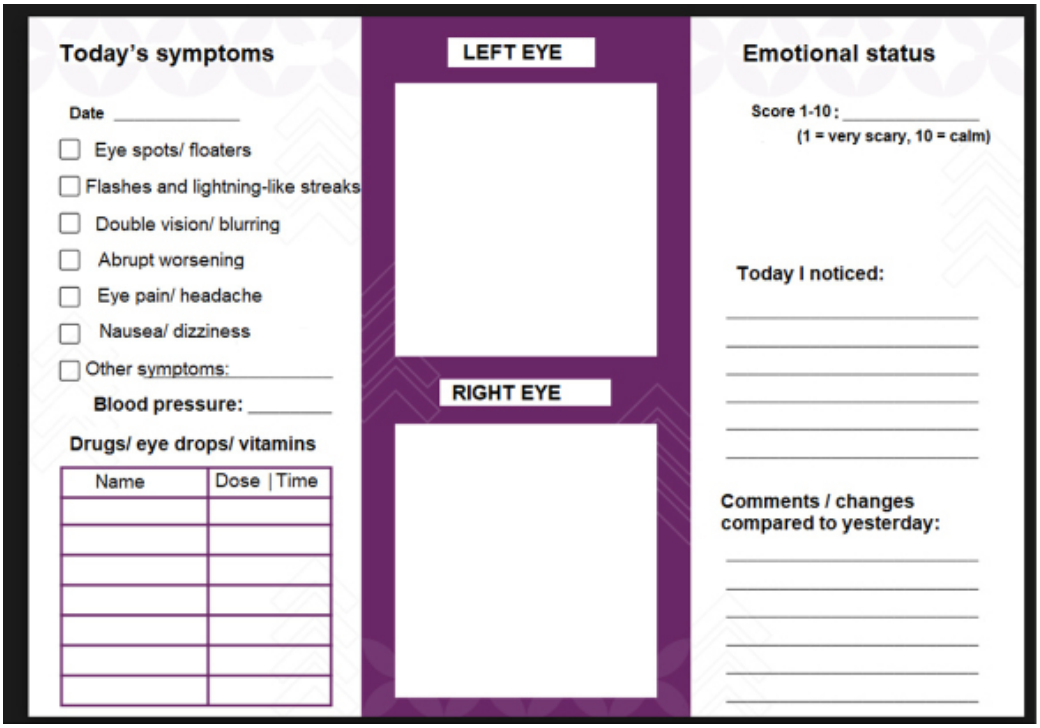

Fig. 1. Vision diary.

Patient's instructions for use: 1. Print the diary template. 2. Fill in by hand. 3. In each cell draw either how your right or left eye views the world outside the window or your favorite picture. 4. You may fill in squares an unlimited number of times and compare and self-assess your vision for correspondence with other measures of self-reported well-being.

Abbreviations

Hospital Anxiety and Depression Scale, HADS; IOP, intraocular pressure; MBI, mine blast injury; OCT, optical coherence tomography; SPIKES, Setting, Perception, Invitation, Knowledge, Emotions, and Strategy/Summary; (a six-step protocol for delivering bad news); TBI, traumatic brain injury.

Література

1. Kessels RP. Patients' memory for medical information. J R Soc Med. 2003 May;96(5):219-22. doi: 10.1177/014107680309600504.
2. Vermeir P, Vandijck D, Degroote S, Peleman R, Verhaeghe R, Mortier E, et al. Communication in healthcare: a narrative review of the literature and practical recommendations. Int J Clin Pract. 2015 Nov;69(11):1257-67. doi: 10.1111/ijcp.12686.
3. Stewart MA. Effective physician-patient communication and health outcomes: a review. CMAJ. 1995 May 1;152(9):1423-33.
4. Zolnierek KB, Dimatteo MR. Physician communication and patient adherence to treatment: a meta-analysis. Med Care. 2009 Aug;47(8):826-34. doi: 10.1097/MLR.0b013e31819a5acc.
5. Vogt L, Stoyanov S, Bergs J, Schröder H, Drachsler H, Klasen M, et al. Are the World Health Organization's Patient Safety Learning Objectives Still Up-to-Date: A Group Concept Mapping Study. J Patient Saf. 2022 Dec 1;18(8):731-737. doi: 10.1097/PTS.0000000000000993.
6. Sansone RA, Sansone LA. Doctor shopping: a phenomenon of many themes. Innov Clin Neurosci. 2012 Nov;9(11-12):42-6.
7. Chang EE, Goldberg JL. Glaucoma 2.0: neuroprotection, neuroregeneration, neuroenhancement. Ophthalmology. 2012 May;119(5):979-86. doi: 10.1016/j.ophtha.2011.11.003.
8. Schmetterer L, Scholl H, Garhöfer G, Janeschitz-Kriegl L, Corvi F, Sadda SR, Medeiros FA. Endpoints for clinical trials in ophthalmology. Prog Retin Eye Res. 2023 Nov;97:101160. doi: 10.1016/j.preteyeres.2022.101160
9. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302-11. doi: 10.1634/theoncologist.5-4-302.
10. Vasconcellos CFC, Pellissari MC, Zin OA, Salles MV, Sallum JMF, Vasconcellos JPC. Breaking bad news in ophthalmology: a literature review. Arq Bras Oftalmol. 2022 Sep 23;87(1):0104. doi: 10.5935/0004-2749.2022-0104.
11. Fuerst N, Watson J, Langelier N, Atkinson R, Ying Gui-Shuang, Pan W, et al. Breaking Bad: An Assessment of Ophthalmologists' Interpersonal Skills and Training on Delivering Bad News. Journal of Academic Ophthalmology: 2018. 10 (1): Article 23. doi:10.1055/s-0038-1667051.