# MINISTRY OF EDUCATION AND SCIENCE OF UKRAINE SUMY STATE UNIVERSITY ACADEMIC AND RESEARCH MEDICAL INSTITUTE

# Eastern Ukrainian Medical Journal

116, Kharkivska st., Sumy 40007, Ukraine e-mail: eumj@med.sumdu.edu.ua

eumj.med.sumdu.edu.ua

ISSN: 2663-5909 (print)/2664-4231 (online)

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**How to cite** / **Я**κ **цитувати статтю:** Kachkovska V. The utilization of the SPIKES protocol within rheumatology practice. *East Ukr Med J.* 2024;12(3):670-677

DOI: https://doi.org/10.21272/eumj.2024;12(3):670-677

#### **ABSTRACT**

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## THE UTILIZATION OF THE SPIKES PROTOCOL WITHIN RHEUMATOLOGY PRACTICE

**Introduction.** The beginning of the patient-physician relationship often involves the delivery of bad news. The work of rheumatologists is unique in that they have to form strong relationships with their patients while delivering bad news. Many rheumatology patients stay with their doctors for their entire lives, which makes it essential to create a positive and caring experience for them. This depends on the physician's professional skills, ability to understand the patient, and engage in respectful and understandable communication when discussing complicated information. Currently, no specific recommendations exist for constructing an appropriate approach for every patient, especially in the case of rheumatology patients. This paper will adapt the SPIKES protocol for rheumatology practice.

Methods. The literature search was done via MEDLINE/PubMed, Scopus, and Google Scholar. Search terms included "Ethics", "Rheumatology", "Bad news", "SPIKES" and "Difficult patient". These keywords were used in different combinations, using a filter box with an option for the recent 5 years. Firstly, articles' abstracts were analyzed, and only articles that met inclusion criteria were included. Also, references from the selected articles were analyzed, except for the older publications and those irrelevant to the specific topic. Since there was not enough information for these requests, we tried to narrow the search by combining the names of various (most common) rheumatological diseases and using them along with the main purpose of the search. Then, we focused on the publications that met criteria and analyzed the sources cited in them. The 'Related Citations' function was also used in the search strategy. In the literature review process, we included 10 MEDLINE/PubMed articles, 4 Scopus articles, and 2 Google Scholar articles.

**Aim.** This paper analyzes utilization of the SPIKES protocol in rheumatology practice.

**Results.** Currently, no studies have been conducted on the utilization

of these approaches in rheumatology practice. There is insufficient data regarding comparison of the effectiveness of different protocols in enhancing communication between the healthcare provider (physician or nurse) and the patient. Effective communication between physicians and patients can be achieved by following the six-step SPIKES approach, which involves specific communication skills.

**Conclusion.** Delivering bad news requires different approaches, but none of them have been specifically tailored for rheumatic disease patients. These patients have unique behavior patterns due to the nature of their illnesses, which can lead to a decrease in their quality of life, limited activity, and painful symptoms. As a result, they often turn to their doctors in a state of personal and mental suffering. Thus, the SPIKES protocol is a useful tool for rheumatology practice.

**Keywords:** SPIKES protocol, bad news, rheumatology, practice guideline, ethics.

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#### **РЕЗЮМЕ**

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## ВИКОРИСТАННЯ ПРОТОКОЛУ SPIKES В РЕВМАТОЛОГІЧНІЙ ПРАКТИЦІ

Вступ. Початок стосунків між пацієнтом і лікарем часто включає повідомлення поганих новин. Робота ревматологів унікальна тим, що вони мають налагодити міцні стосунки зі своїми пацієнтами, повідомляючи при цьому погані новини. Багато пацієнтів з ревматологічними захворюваннями залишаються зі своїми лікарями все життя, тому важливо створити для них позитивний досвід і відчуття турботи. Це залежить від професійних навичок лікаря, його здатності розуміти пацієнта, а також підтримувати шанобливе та зрозуміле спілкування під час обговорення складної інформації. Наразі не існує конкретних рекомендацій щодо побудови відповідного підходу до кожного пацієнта, особливо у випадку пацієнтів з ревматологічними захворюваннями. У цьому документі буде адаптовано протокол SPIKES для ревматологічної практики.

Методи. Пошук літератури здійснювався MEDLINE/PubMed, Scopus i Google Scholar. Пошукові терміни включали «етика», «ревматологія», «погані новини», «SPIKES» та «важкий пацієнт». Ці ключові слова використовувалися в різних комбінаціях, пошук вівся по статтях за останні 5 років. По-перше, були проаналізовані анотації статей, і лише ті статті, які відповідали критеріям включення, були обрані для дослідження. Також були проаналізовані посилання з вибраних статей, за винятком давніх публікацій і тих, що не мають відношення до конкретної теми. Оскільки інформації для цих запитів було недостатньо, спробували звузити пошук, поєднавши назви різних (найпоширеніших) ревматологічних захворювань і використавши їх разом із основною метою пошуку. Потім ми зосередилися на публікаціях, які відповідали критеріям, і проаналізували цитовані в них джерела. У пошуковій стратегії також використовувалася функція «Related Citations». У процесі огляду літератури ми включили 10 статей з MEDLINE/PubMed, 4 статті з Scopus і 2 статті з Google Scholar.

**Мета**. У цій статті аналізується використання протоколу SPIKES у ревматологічній практиці.

Результати. Дослідження щодо використання цих підходів у ревматологічній практиці на сьогодні не проводилося. Даних щодо порівняння ефективності різних протоколів у покращенні комунікації між постачальником медичних послуг (лікарем або медсестрою) та пацієнтом недостатньо. Ефективної комунікації між лікарями та пацієнтами можна досягти, дотримуючись шестиетапного підходу SPIKES, який включає певні навички спілкування.

**Висновок**. Повідомлення поганих новин вимагає різних підходів, але жоден із них не був спеціально розроблений для пацієнтів з ревматичними захворюваннями. Ці пацієнти мають унікальні моделі поведінки через характер їхніх захворювань, який призводить до зниження якості їхнього життя, обмеження активності та виражених симптомів. Через це вони часто звертаються до лікарів у стані особистих і душевних страждань. Таким чином, протокол SPIKES є корисним інструментом для ревматологічної практики.

**Ключові слова**: протокол SPIKES, погані новини, ревматологія, практична настанова, етика.

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#### INTRODUCTION / BCTYII

The relationship between a patient and their physician often begins with the delivery of bad news. Rheumatologists have a unique role in fostering these relationships, as they are often the ones responsible for delivering bad news to patients. Many rheumatology patients remain with their physicians for the life-long term, and the rheumatologist's primary aim is to ensure that this relationship is positive and compassionate. This is dependent on the physician's level of professional expertise, their ability to empathize with their patient and to communicate challenging information. Creating a perfect approach for each patient is almost impossible, and no established frameworks are in place for rheumatology patients.

In their work on the ethics of rheumatology, Paul L. Romain and his coauthors offer perspectives and questions for discussion [1]. They view ethics as an essential tool for rheumatologists in their day-to-day practice, enabling them to make moral judgments guided by fundamental principles. The authors also identify several common ethical dilemmas that doctors encounter regularly in their work [1]. Managing patients with chronic diseases presents universal ethical dilemmas that are seldom discussed in the ethics literature. However, every rheumatologist confronts numerous ethical queries, such as communicating the diagnosis and guiding patients to adhere to prescribed treatment.

"Bad news" is "any information which adversely and seriously affects an individual's view of his or her future" [2]. When delivering bad news, a physician must gather all necessary data from the patient, provide clear and concise information that meets the needs and goals, offer emotional support, and work with the patient to develop a treatment plan which is to be mutually agreed upon [3]. These key objectives must be met in order to ensure the best possible outcome for the patient.

Different algorithms for delivering "bad news" were developed and adapted to the clinical practice. The algorithm most commonly used and described in the literature is SPIKES protocol. SPIKES was invented and implemented by a group of oncologists affiliated with MD Anderson Cancer Center (University of Texas, USA) and Sunnybrook Regional Cancer Center (Toronto, Canada) [3]. Initially, it was recommended for use in oncology patients, although later it was more widely adopted. The aim of the SPIKES is to build a model of delivering bad news and provide medical professionals with required tools which can increase physicians' confidence. At the same time, having a strategy for addressing patient's distress during the disclosure process may encourage their participation in treatment decisions. SPIKES consists of the six easy steps to follow in clinical practice, which include: S -Setting up for the interview, P - the assessment of patient's Perception, I – obtaining the patient's Invitation, K – providing the Knowledge to the patient, E – Empathic attitude to the patient's Emotions, S – Summarizing the Strategy [3].

This paper examines implementing the SPIKES protocol in rheumatology practice. Before delivering negative or severe news to a rheumatology patient, various factors must be considered. Firstly, based on primary care data, the frequency of challenging patients ranges from 15 to 30% [4]. Challenging patients are individuals who present with arduous behavior, agitation, desperation, or even animosity towards healthcare professionals [5]. In rheumatology practice, every patient may pose challenges for a range of reasons. The following are examples of several challenging cases. The patients consented for the publication of their cases.

#### CASE DESCRIPTION AND ANALYSIS

Patient 1. There was a knock on my office door (thunderous, it seemed like somebody kicked in the door with their feet). An adult man, around forty years old, about two meters tall, burst in and began to shout. The tone of his voice resembled the roar of a bear, and he said he had been ill for about three months. His small joints were swollen and very sore, and working as a loader, he was incapacitated during those there months. He was newly married at the time. He consulted several orthopedists, and they prescribed painkillers, which brought relief for a short period; a neighbor recommended seeing a rheumatologist. "You don't understand! I can't work anymore, I can't sleep with my wife, or God, it has completely ruined my life," and he started to cry.

Patient 2. Sometimes, it can take months, even years, from the onset of symptoms to diagnosis. This is especially common in patients with ankylosing spondylitis, since the diagnosis is initially confused with other diseases. Despite treatment, patients lose their physical ability and, at times, their faith in doctors. A thirty-four-year-old man was admitted. He did not make eye contact. Five years ago, he lost his left leg and left arm due to electro trauma; before that, he was a master of sports in swimming and a winner of many international competitions. He spent these five years with different doctors and followed various treatment plans, some of which were very costly, and none were effective. During this first consultation, he seemed to silently hate the physician and the hospital setting; he did not trust the rheumatologist.

Patient 3. The patient was brought into the office in the arms of two other men. The fifty-year-old patient smilingly said, "You know I'm actually ok, just can't walk." His very emotional wife followed him; she said this was the third rheumatologist they had consulted and that none had helped them, so she treated him by herself.

From the whole story, it became clear that the treatment previously prescribed was correct, but did not bring quick response, and his wife gave him medication that aggravated his condition and caused inability to walk.

Dealing with such different patients in daily practice, the rheumatologist must realize that every patient's emotions and actions have a background. You can not blame the rude kick in the door (the patient was physically unable to knock with his hands), the shout of the patient (emotions associated with acute pain), emotional indifference (the patient was tired of numerous medical procedures; the patient at a young age lost limbs and his ordinary life full with joy and happiness).

So, I had to inform each of these three patients about their diagnosis and have them involved in active continuous treatment, which was usually more complicated. Therefore, I would like to discuss several peculiarities in rheumatology practice which require adaptations to the SPIKES Protocol.

Before talking to a patient, make sure that you have enough time (it takes 30 to 40 minutes to discuss the diagnosis and prescribe primary treatment). You need a comfortable, quiet environment and should silence a mobile phone. At the patient's request, they are allowed to have a close relative or friend with them which can also be helpful to the physician.

- 1. **SETTING**: Both physician and patient should be sitting in an enclosed area. There should be no obstructions between you and the patient (table or monitor). Make eye contact before you start talking. Empathy and honesty are our primary tools. In conversation with the patient, the pronoun "We" instead of "I" or "You" is recommended. Do not use the phrase "I have bad news for you." Instead, start with comments like, "We went through many examinations. As you may recall, I had some doubts about the symptoms you described on the last visit, so we did additional tests and x-rays of the joints. We agreed not to discuss previous diagnoses and not to read online forums before receiving the final results, and I know that you took my advice, thank you very much for that. Now we will discuss reliable and evidentiary sources of information." Before making a diagnosis, list the laboratory and instrumental tests results that confirm patient's disease. Use the same diagnostic criteria as in your practice but reveal them in simplified, patient-friendly language.
- PERCEPTION: Elicit what the patient knows so far. Sometimes, patients may have some information about their condition. For example, some patients get their information from TV,

movies, or bloggers which may be inaccurate. Also, some patients have close relatives with the same diagnoses, and some read information online. At this stage, it is crucial to discuss what is accurate and what is not to reduce anxiety.

- 3. INVITATION: Ask permission before proceeding. The next step of discussing a treatment strategy is necessary to clarify whether the patient has any doubts or needs clarifications about their diagnosis and whether further conversation is possible.
- 4. KNOWLEDGE: Minimize jargon and detail. The conversation with the patient should be clear and accessible to them, as this influences their attitude and adherence. During the consultation, you need to check the patient's level of perception and understanding. For example, some patients react very emotionally to the diagnosis. One day, a 63-year-old woman burst into tears after being diagnosed with rheumatoid arthritis, saying, "Doctor, I have just bought a new coat." Of course, in this case, you need to pause, stabilize the patient's psycho-emotional state, and then comment on the treatment.
- 5. EMPATHY: Silence is often best. Make it clear to the patient that they are not alone in this struggle. Use phrases like: "This is our common task, to take control of your disease, and today, we have all the possible tools for this." Apply to the patient as a person: "You have wonderful grandchildren, and I want to hear from you next time about your family cycling trips." Rheumatology practice today has a wide range of treatment options and a high chance of remission, so when medically justified, give the patient hope for the better.
- 6. STRATEGY: Explain what is next. In most cases, rheumatic diseases are treated with immunosuppressive drugs. Ensuring the patient understands the prescribed schemes (you may draw diagrams, write in calendars) is essential as well as making sure that the patient understands the information provided. Ask if the patient has a phobia of injectable drugs (tablets can sometimes replace them). In addition, the patient should undergo regular laboratory tests to monitor the effectiveness and safety of therapy. Some patients may ignore this recommendation, especially if they see an improvement in their condition, so you must be persistent. Emphasize the seriousness of prescribed drugs, mechanism of action (immunosuppression), and mandatory testing for possible side effects of which the patient may not be aware or recognize.

Summing up the phrase: "My main task is to help you, but I can not do it myself; I need your help and commitment to my recommendations so that I will be waiting for positive news and good test results in 3 months." This will help the patient feel that you care.

The SPIKES protocol was effectively used to facilitate communication with rheumatology patients, but further research involving a larger patient population with various rheumatological conditions may be necessary to establish it as a general tool.

Methods. The literature search was done using the search strategy recommended in the literature via MEDLINE/PubMed, Scopus, and Google Scholar [6]. Search terms included "Ethics", "Rheumatology", "Bad news", "SPIKES", and "Difficult patient". These keywords were used in different combinations, using a filter box with an option for the recent 5 years. Firstly, articles' abstracts were analyzed, and only articles that met inclusion criteria were included. Also, references from the selected articles were analyzed, except for the older publications and those irrelevant to the specific topic. Since there was not enough information for these requests, we tried to narrow the search by combining the names of various (most common) rheumatological diseases and using them along with the main purpose of the search. Then, we focused on the publications that met criteria and analyzed the sources cited in them. The 'Related Citations' function was also used in the search strategy. In the literature review process, we included included 10 MEDLINE/PubMed articles, 4 Scopus articles, and 2 Google Scholar articles.

**Results and discussion.** Various protocols have been developed for delivering bad news, including SPIKES, ABCDE [7], Kaye's 10 step model [8], PEWTER [9], and BRAKES [10]. Table 1 provides a brief overview of the approaches that were mentioned.

Currently, no studies have been conducted on the utilization of these approaches in rheumatology practice. There is insufficient data regarding comparison of the effectiveness of different protocols in enhancing communication between the healthcare provider (physician or nurse) and the patient. In one study, the authors analyzed SPIKES and PEWTER evidence-based communication models in the oncology practice, summarizing that they were equally effective and the two protocols could complement each other in some cases [11].

Effective communication between physicians and patients can be achieved by following the six-step SPIKES approach, which involves specific communication skills. [3]. Not all bad news will require all the stages of SPIKES, but when it does, they must follow one another [3].

*Table 1 – Comparative features of different protocols for delivering bad news* 

Model	SPIKES	PEWTER	BRAKES	ABCDE	Kayes' 10 step model
Application	Designed for cancer patients, implemented in various clinical fields	Implemented for emergency medicine	Various clinical areas	Various clinical areas, including dentistry	Various clinical areas
Preparatory and assessment stage	Setting, Perception (patient's) Invitation	Prepare, Evaluate	Background Rapport Explore (the patient's current knowledge)	Advance preparation Build a therapeutic environment/ relations hip	<ol> <li>Preparation.</li> <li>Determine what the patient know and</li> <li>If more information is needed.</li> </ol>
Delivering bad news	Give <b>K</b> nowledge	Warning with a brief statement Telling the news	Announce	Communication well	<ul><li>4. Give warning shots.</li><li>5. Allow to refuse the information.</li><li>6. Explain if requested.</li></ul>
Assessment of the post- news perception and emotions validation	Empathy: Adress the patient's emotions	Emotional response	<b>K</b> indling	Encourage and assess Emotions	Listen to concerns.     Encourage feelings
Summary for future treatment planning and follow-up	Strategy and summary	Regrouping preparation	Summarize		9. Summarize. 10. Follow-up

Previously, several studies proved the effectiveness of this protocol in oncological, neurological, and psychiatry practice [3, 12, 13, 14]. A study published in the journal "Knee" discussed the use of the SPIKE protocol in rheumatology practice [15]. The authors of the paper examined the effectiveness of SPIKES in a group of patients who were receiving an intra-articular joint injection. Based on the questionnaire results, the authors concluded that SPIKES did not provide any significant benefits to the patients [15]. However, this study focused on a one-time and short-term medical procedure; however, the SPIKES protocol can help patients come to terms with their diagnosis and equip them with the necessary tools to manage their disease in the long run. It can also help to facilitate a positive and productive long-term relationship between a patient and a physician [16].

P.S. Patient 1 has been my patient for seven years. He calls me on his Birthday every year saying, "Dr., it is my Birthday today, but our first toast is always to you, Dr!"

Patient 2 is currently protecting our Homeland. Before the full-scale war, he had a complete remission, and every three months, he came to my office with the words, "Hey Doc, I have just came to say that I am ok, because I know that you care," and he had plans to get married.

Patient 3. His disease is under total control. And occasionally, he refers his friends with similar issues to me for consultations.

#### CONCLUSIONS / BUCHOBKU

Patients with rheumatological conditions exhibit varied patterns of behavior, depending on the nature of their illnesses. These conditions often result in a decline in their quality of life, limitations in their usual activities, and painful symptoms that can be either chronic and draining or acute and sporadic. As a result, they seek medical attention while experiencing

unpleasant emotions, personal and mental distress. Delivering bad news requires different approaches, but none of them have been specifically tailored for rheumatic disease patients. Based on our experience and literature review the SPIKES protocol demonstrated that it is a workable and useful tool for rheumatology practice.

#### CONFLICT OF INTEREST / КОНФЛІКТ ІНТЕРЕСІВ

The authors declare no conflict of interest.

#### ACKNOWLEDGEMENTS / ПОДЯКА

The author would like to express a special gratitude to the Armed Forces of Ukraine for the ability to continue our work in our home town of Sumy. Also, I would like to express a special appreciation to Emily E. Anderson, Ph.D., M.P.H., Professor, and Nanette Elster J.D., M.P.H., Associate Professor, Neiswanger Institute for Bioethics and Healthcare Leadership, Stritch School of Medicine, Loyola University Chicago, for motivating and providing with strong spiritual support, and editorial work on this article.

#### FUNDING / ДЖЕРЕЛА ФІНАНСУВАННЯ

The work is supported by the Loyola University Chicago-Ukrainian Catholic University Bioethics Fellowship Program, funded by the National Institutes of Health Fogarty International Center (D43TW011506).

#### AUTHOR CONTRIBUTIONS / ВКЛАД АВТОРІВ

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

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Received 09.04.2024 Accepted 22.05.2024

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Одержано 09.04.2024 Затверджено до друку 22.05.2024

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