

# Communicating a negative prognosis by primary care physicians

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## Abstract

The right to information about one's own health condition, including adverse prognosis, derives from the provisions of the Act on Patients' Rights and Patients' Ombudsman and the Code of Medical Ethics. Appropriate tools, such as the SPIKES protocol, can support doctors in communicating a poor prognosis. The aim of this study was to investigate how doctors working in primary care communicate information about an adverse prognosis to their patients and their relatives. 72.2% of the 744 surveyed primary care physicians claimed that they raised the issue of death or adverse prognosis with the patient when directly asked, while 63.3% provided the information themselves. However, 15.1% of doctors did this in the absence of the patient without the patient's consent, and 40.2% of respondents indicated that they passed on information about a poor prognosis to the family with the patient's "implicit consent". In the study, in a selected group of primary health care (PHC) doctors who also specialised in palliative medicine, 100% of respondents declared that they had the autonomy to discuss a poor prognosis. To support GPs in exercising the patient's right to information about their condition, it is important to use the tools and competences for communicating a poor prognosis and to use the developed relationship with the patient and their relatives to communicate a poor prognosis openly. Continuous training, including in psychological competence, with psychological support for PHC doctors and the implementation of appropriate working protocols can help.

**Key words:** death, prognosis, primary health care, communication, palliative care.

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## INTRODUCTION

Effective doctor-patient communication plays a key role in building the relationship between them, laying the foundations on which such important tasks as making an accurate diagnosis, giving the right advice, providing therapeutic guidance, and their effective implementation by the patient can be carried out [1, 2]. Ultimately, any doctor-patient communication is aimed at improving the health and medical care of the patient. Studies on doctor-patient communication have shown patient dissatisfaction, even though many doctors considered this communication to be adequate or even excellent, indicating that doctors themselves tend to overestimate their skills in this area [3]. The above also applies to family doctors.

The model of communication has evolved over the years from a paternalistic approach to a more

individualistic one, characterised by a partnership between doctor and patient [4]. One of the key elements of communication is the communication of a poor prognosis. Back in the 1950s–1970s, it was still maintained that information about a poor prognosis should not be communicated to the patient because of the adverse effect on their health and well-being, and its open communication was considered inhumane [5]. This was particularly true for patients with cancer [6]. Currently, the essential 3 goals of doctor-patient communication include building a good relationship, facilitating information exchange, and involving the patient in the decision-making process [2]. Good doctor-patient communication helps regulate patients' emotions and facilitates the comprehension of medical information. It allows for the identification of needs, perceptions, and expectations on the part of the patient.

## Legal basis for obtaining information about one's own health

In accordance with the provisions of article 31 of the Act on the Professions of Doctor and Dentist of 5 December 1996 [7] and article 9 of the Act on Patients' Rights and Patients' Ombudsman of 6 November 2008 [8], it is the doctor's duty to provide the patient with information on his or her medical condition and any medical procedures to which he or she may be subjected, together with a discussion of their potential consequences and impact on his or her health. The doctor may refrain from doing so only at the express request of the patient or if the prognosis is inauspicious for the patient and, in the doctor's judgement, the patient's best interests are in favour of not providing the information. In such case, however, he or she is obliged to inform the patient's legal representative or authorised person of the patient's condition.

If a doctor decides to withdraw treatment, he or she should inform the patient sufficiently in advance of the intention in question and indicate other options for obtaining services. When providing information, the doctor is obliged to act with respect for the dignity and intimacy of the patient, as per the Act on Patients' Rights and Patients' Ombudsman.

## SPIKES protocol

Protocols have been developed to help clinicians deal with the management of unhelpful news to the patient, and these provide effective support in undertaking difficult conversations with patients.

The SPIKES [6] protocol is a communication tool presenting a scheme to follow when communicating bad news. The SPIKES protocol consists of 6 elements, as shown in Table 1.

The use of the above diagram, thanks to its structured, logical form, can significantly facilitate communication and the building of the doctor-patient relationship. Reducing the patient's suffering by showing support is one of the goals of medical care.

## Patients' expectations

The perception of the information provided is significantly influenced by the way the patient learns of an unsuccessful prognosis. It also has a significant impact on the willingness to continue treatment under the supervision of a particular doctor [9].

The aim of this study was to investigate how doctors working in primary care communicate information about adverse prognoses to their patients and their relatives.

## MATERIAL AND METHODS

The survey was conducted in the form of an online questionnaire available to doctors working in primary care. According to the 2019 study, their total number is 43,130 [10]. The survey was divided into a section collecting demographic data (5 questions) and employment information and a content section (3 questions).

The research problem was formulated in the course of the authors' work and review of the literature

**Table 1.** SPIKES Protocol

S (setting)	Appropriate environment; during the interview, ensure privacy, make the patient comfortable, establish an appropriate rapport. The patient should be the one who decides on the participation of a loved one in the conversation
P (perception)	Learning about the state of the patient's knowledge; before disclosing information, the doctor should assess the patient's perception of their situation and the status of the patient's knowledge of the current disease, so that any misconceptions the patient may have can be corrected
I (invitation)	Invitation to a conversation; at this stage it is important to know the patient's expectations in terms of the detail of the information to be communicated and his/her readiness to receive these messages. The knowledge acquired will allow for adapting the form and content of the information provided
K (knowledge)	Communicating information; to reduce the patient's unpleasant experience, it is useful to warn the patient of impending news before giving bad news. During the conversation, use vocabulary appropriate for the patient's cognitive abilities. Information should be given gradually in small portions, making sure that the patient has understood its meaning. The patient should be given space to think and ask questions of their own
E (emotions and empathy)	Emotions and empathy; the patient should be given the opportunity to express his or her emotions and become accustomed to new information. The doctor's role is to show empathy and understanding for the patient's plight
S (strategy and summary)	Action plan and summary; if the patient is ready to discuss further management, this should be done, involving the patient in the decision-making process. By being presented with possible pathways, patients feel a greater sense of control over their current situation and are therefore less likely to experience anxiety and uncertainty

and factual reports on the communication of a bad prognosis. The questionnaire was developed after a review of the literature (see introduction) on the topic under discussion and a series of interviews between the authors and key individuals related to the scope of the study. At this stage, the essential questions and expectations of the study's outcomes were formulated. They were collected in the form of a questionnaire using questions with answer suggestions, open questions, and questions using a Likert scale.

The survey was conducted using typeform.com, an on-line data collection system, Google Analytics web analytic system, and Google Docs files. Once the tools used were up and running and configured, a pilot study was performed on a group of 10 doctors, checking that the questions were clearly formulated and that there were no technical difficulties in answering them.

Using Cochran's modified formula, for the total number of respondents, i.e. 43,130 doctors, maintaining a 95% confidence interval ( $\alpha = 0.95$ ), a fraction size of 0.5 (unknown a priori response rate) ( $p = 0.5$ ), and a maximum error of 5% ( $d = 0.05$ ), the number of respondents could not be lower than 381.

The survey was made available between 10 June 2020 and 10 September 2021. The timing of the research data collection coincided with the SARS-CoV-2 virus pandemic. The authors decided to carry out the survey in the only manner that gives full security to the respondents, i.e. through an online questionnaire. Information about the survey was communicated through classical channels (oral and written invitations, information at events) and on-line channels (newsletter, website, forum of primary care physicians in a group on the portal of the facebook.com), which aimed to invite all doctors to the survey, regardless of their daily use of electronic media.

The authors aimed to collect data from 1% of the physicians employed in primary care in Poland [10], which was achieved, and then the data collection period was closed. The researchers collected data using a questionnaire only from directly surveyed doctors.

The research was conducted in accordance with the Declaration of Helsinki. The consent of the Bioethical Committee of the Medical University of Wrocław was obtained, decision number KB 472/2020, registration number CWN UMW: SUB. C290.19.054.

The results collected from 744 doctors practising in primary care on a daily basis were analysed. Two not fully completed questionnaires were rejected. Sixteen respondents answered that they did not work in primary care; consequently, the algorithm embedded in the questionnaire automatically prevented them from filling out the questionnaire.

## Statistical analysis

The analysis was performed in Statistica 13.1. In descriptive statistics, the Shapiro-Wilk test was used to test normality. Mean values and 95% confidence intervals (95% CI) were applied for normally distributed continuous variables. At the same time, medians and quartile values (Q25, Q75) were applied for the others. Spearman's correlation coefficient was performed to evaluate the relationship between parameters. *P*-values less than 0.05 were considered statistically significant.

## RESULTS

Of the 726 respondents, more than 85% had a professional length of service as a primary health care (PHC) doctor of at least one year, with more than half of the doctors working in PHC for at least 6 years. Only one-eighth of the respondents had less than one year of work experience (Fig. 1).

Most of the respondents mentioned the PHC as their main place of work (87.6%), and only a minority of them (3.3% of respondents) worked in palliative care at the same time. In contrast, 9.2% of respondents admitted that the PHC was not their only or main workplace (Fig. 2).

As shown on the graph, the average working time for most respondents ranged from 20 to 40 hours per week. One-quarter of respondents spent more than 40 hours working in the PHC, and only 4.4% of respondents spent less than 10 hours per week working (Fig. 3).

Three-fourths of the respondents to the questionnaire were family medicine specialists or were studying and working towards this specialisation. Some respondents were specialists in internal medicine (16.8% of respondents), with 8% specialising in both family medicine and internal medicine. Twelve palliative medicine specialists (1.6%) and 20 paediatricians (2.7%) were also included in the study.

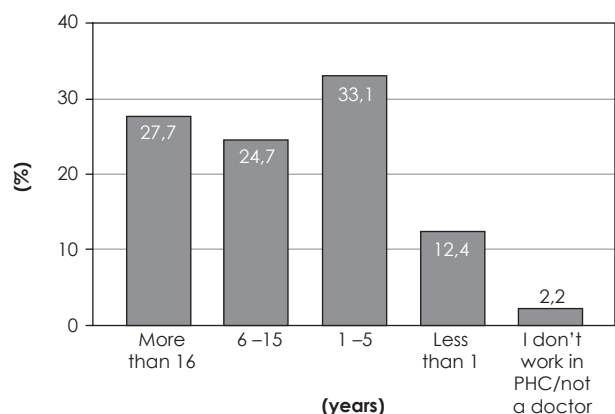


Fig. 1. Length of seniority of respondents as primary health care doctors

PHC – primary health care

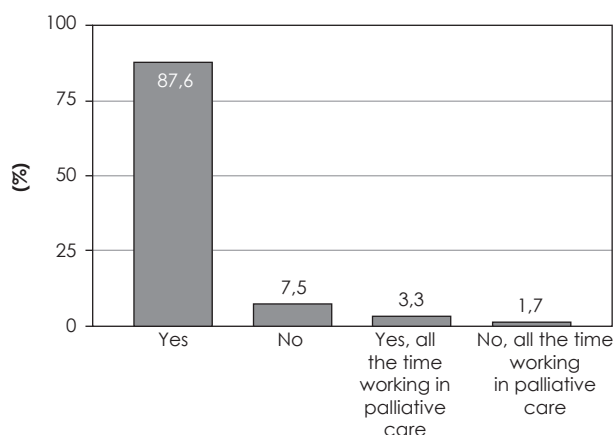


Fig. 2. Answer to the question "Is primary health care your main workplace?"

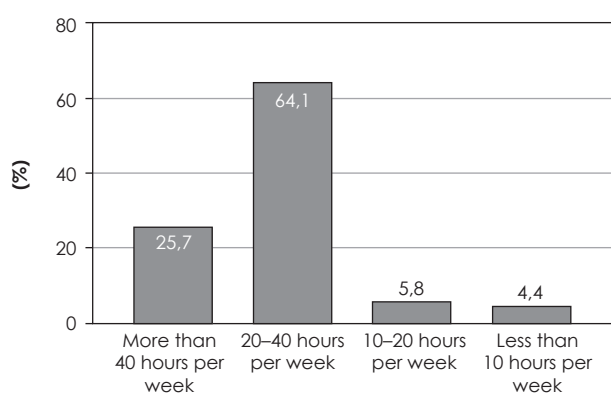


Fig. 3. Number of hours spent, on average, per week working in primary health care

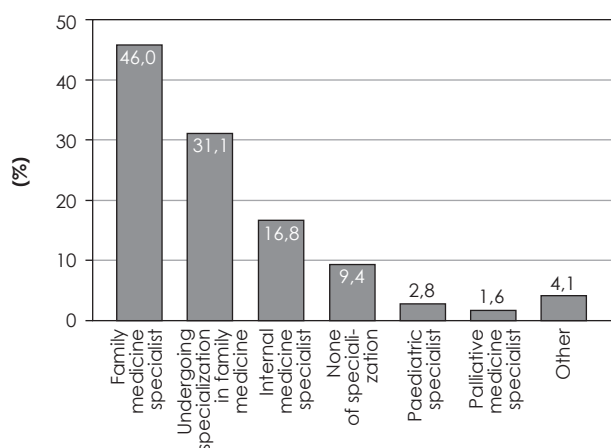


Fig. 4. Respondents' medical specialisations

atric specialists (2.8%) participated in the questionnaire (Fig. 4).

## DISCUSSION

Most of the doctors surveyed (72.2%) raised the issue of death or poor prognosis in a conversa-

tion with the patient at the patient's direct request, while of their own volition a total of 63.3% did so (but with their chosen criteria for making this decision, as indicated in Figure 5). Also, in the selected group of PHC doctors who also specialised in palliative medicine, 100% of respondents declared that they had the autonomy to discuss a poor prognosis.

The study revealed that the greatest independence in the provision of information on poor prognosis was presented by primary care physicians with 1-5 years of work experience ( $n = 178$ , 72.4% of the study group), and the least independence by physicians working for more than 16 years ( $n = 110$ , 53.4% of the study group). The study showed that with the increase in working time, independence initially increased (up to 5 years of work) and then systematically decreased. The groups differed in a statistically significant way ( $p = 0.005$ ). At the same time, physicians who never communicated a poor prognosis to a patient voluntarily dominated in the group with the youngest seniority ( $n = 6$ , 6.5% of the study group working for less than one year), while in the populations working longer it was, respectively, 2.4% (seniority 1-5 years), 2.2% (6-15 years of work experience), and 3.9% (more than 16 years of work experience) (Tab. 2). A statistically significant difference was obtained for the extreme populations (seniority shorter than one year and seniority longer than 16 years,  $p = 0.006$ ).

Statistical significance was not reached for the data concerning the differences in the communication of poor prognosis (*I provide information myself or I never provide such information*) between physicians with or acquiring a specialisation in family medicine ( $p = 0.06$ ) (Figs. 6, 7).

Analytical difficulty was found regarding the impact of the average weekly working time on the transmission of poor prognosis. In the groups working the shortest (less than 10 hours/week in PHC or 10-20 hours/week) there were no physicians declaring that they never communicated a poor prognosis to patients. However, data points out that these doctors usually had a different specialisation (e.g. paediatrics [12 out of 32 physicians working up to 10 hours a week] or internal medicine [another 6 out of 32 physicians working up to 10 hours a week] and palliative medicine [another 6]). As a result, the data obtained from the study did not allow us to determine whether it was the working time or the second specialisation that affected the communication of poor prognosis.

The main place of work had a statistically significant effect ( $p = 0.002$ ) on providing information about a poor prognosis to relatives/caregivers of the patient. Only with the explicit consent of the patient, 47.6% of physicians working mainly in PHC ( $n = 302$ ) did so, compared to 70.4% of phy-

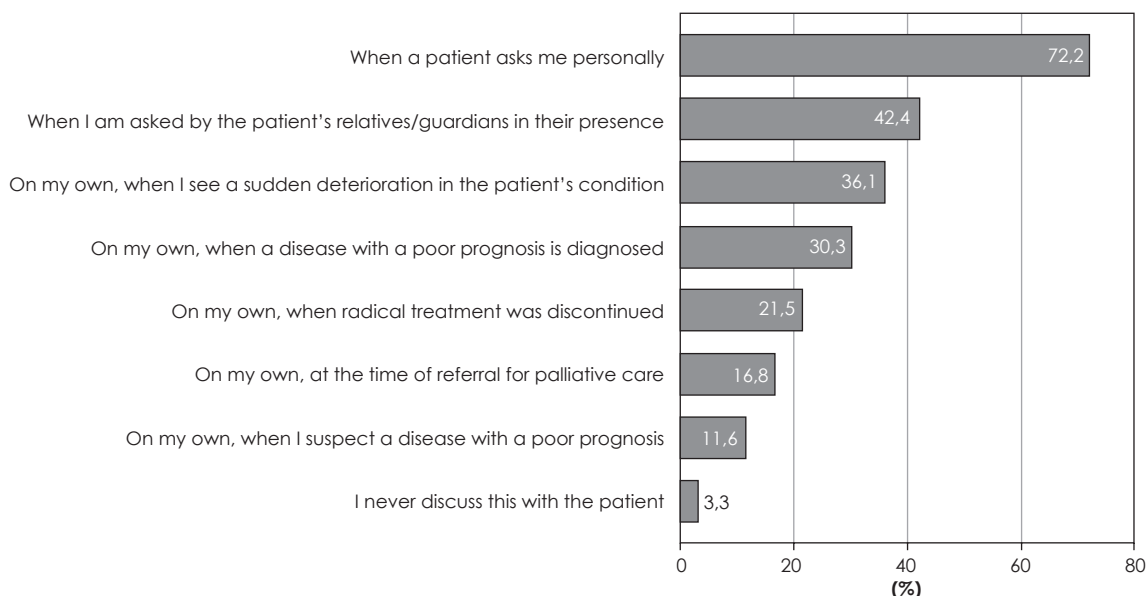


Fig. 5. Situations in which the interviewed doctors raise the issue of death or another bad prognosis with their patient

Table 2. Seniority and independence in communicating poor prognosis

Work experience (years)	Physicians total number (N)	Physicians reporting poor prognosis INDEPENDENTLY		Doctors NEVER report a poor prognosis	
		(n)	%	(n)	%
Less than 1 year	92	54	58.7	6	6.5
1–5 years	246	178	72.4	6	2.4
6–15 years	184	118	64.1	4	2.2
More than 16 years	206	110	53.4	8	3.9

sicians working in primary care as their additional place of work ( $n = 38$ ). No statistically significant differences were found for other ways of conveying a poor prognosis to relatives/caregivers; the significant differences are summarised in Table 3.

What is noteworthy in the study is that 15.1% of PHC doctors declared passing on information about a bad prognosis to the patient's family without first obtaining the patient's consent and in the absence of the patient. 40.2% of respondents mentioned that they passed on information about a bad prognosis to the family with the "presumed consent of the patient", with a further 3.6% of respondents doing so without even the "presumed consent of the patient" being supported, without the patient's knowledge. In addition, 51.5% of the physicians surveyed declared unequivocally that they did so only after obtaining the patient's consent.

Studies have shown that many patients had a negative view of a conversation in which they have been given bad news. They cited the doctor's tactless behaviour during the interview, insufficient time devoted to providing information, lack of attention from the doctor, use of incomprehensible medical jargon, and too little information on diagnosis and options for further management as the most

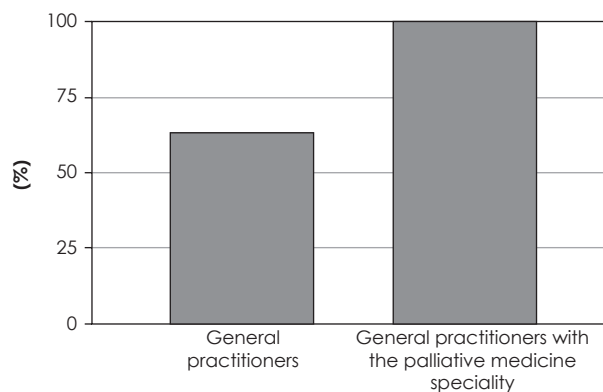
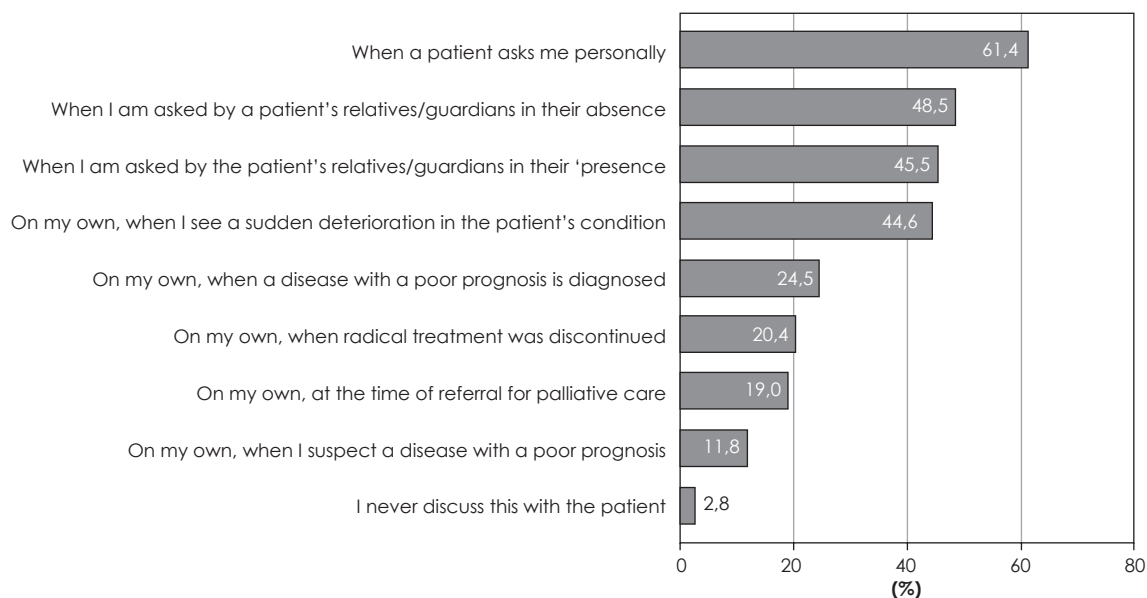


Fig. 6. Independently raising the issue of death or poor prognosis in a conversation with a patient

common reasons for this assessment. Patients primarily identified the sincerity of the doctors and their approach to the situation, as well as their sense of trust in the leading specialist, as factors determining a positive perception.

From the perspective of the clinician breaking bad news, it is very important to determine the patient's current state of knowledge (P – perception) and his or her expectation of the amount of information to be communicated (I – invitation). The complexity of patients' information needs and preferences makes



**Fig. 7.** Situations in which the interviewed doctors raise the issue of death or other bad outlook with their patient's relatives or caretakers

**Table 3.** Discussing the health condition of a patient with a poor prognosis with relatives/caregivers of the patient

Main occupation is GP	All	Physicians providing prognosis only with the patient's explicit consent		Physicians providing prognosis with the consent of the patient's family		Doctors giving prognosis without the patient's knowledge		Doctors communicating the prognosis even if the patient did not want it	
		(n)	%	(n)	%	(n)	%	(n)	%
YES	634	302	47.%	54	8.5	24	3.8	6	0.9
NO	54	38	70.%	6	11.1	2	3.7	0	0.0

the doctor's role in this aspect difficult. Patients want to know the truth about their current state of health, although the range of information desired varies [11, 12]. The majority of patients prefer to receive full information regarding their situation and further management (50–70% of patients, depending on the circumstances) [13]; however, many patients expect to be informed only of the necessary elements required to take appropriate action, which may be conditioned by the fear of receiving bad news that could upset them and their relatives [14]. However, they also want to be involved in the decision-making process (43% as decision leader, 47% in collaboration with the doctor – in a survey of prostate cancer patients) [15]. In such case, the patient's decision should be respectfully accepted, and the remaining information should be passed on to a close person designated by the patient. Also note that, in the case of certain illnesses, informing relatives is even a prerequisite for appropriate treatment. It is also important to obtain information from the patient during each consultation about their information needs, as these may change over time [15].

A conversation in which unhelpful information is passed on is a source of stress not only for patients but also for doctors [16, 17]. Based on a survey of Pol-

ish physicians, it was found that the majority of professionals communicating bad news in their daily practice describe their communication skills as good, based on knowledge acquired during dedicated courses, studies, or specialisation training, although almost 90% of respondents were primarily guided by intuition when communicating bad news [18]. Respondents mentioned communicating the end of causal treatment message and preparing the patient and their relatives for death as the most difficult topics discussed with patients. The reactions and emotions shown by patients are considered the most challenging aspect of such conversations [18]. However, it is a reason for concern that as little as 20% of doctors are familiar with protocol-based communication techniques (e.g. SPIKES) for breaking bad news. Clearly, this shows a need for intensified education on how to inform patients of an unsuccessful prognosis, as well as an emphasis on communication skills training tailored to the needs of doctors. Interpersonal skills training, particularly in managing emotions and using appropriate communication techniques, can be an effective tool to help you cope more effectively when having difficult conversations [16, 18].

Furthermore, according to the literature, the transmission of information about a bad prognosis or death may be affected by an unprocessed fear of death among medical staff themselves. A GP's contact with a dying patient can instil fear of his or her own death. Reworking thanatic anxiety can be an important element in strengthening the PCH doctor in his/her relationship with the patient with a bad prognosis [19].

## CONCLUSIONS

Communicating bad news is an essential skill for any primary care physician. This study collected preliminary data on the communication of information by this group of doctors, and the results highlight the difficulties in directly implementing the patient's right to information about their own health. It is important to support GPs in their use of tools and competences to communicate a bad prognosis and to use the developed relationship with the patient and their relatives to communicate openly a poor prognosis. Continuous training is required, including in psychological competence combined with psychological support for PHC doctors. Familiarity with specific protocols, such as SPIKES, may also prove useful. Aiming to convey the whole truth by using an appropriate form of communication coincides with patients' expectations.

The conducted study coincided with the SARS-CoV-2 virus pandemic. The data collected in the study concerned the period preceding the pandemic, about which the surveyed doctors were warned at the beginning of the study.

*The authors declare no conflict of interest.*

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