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BREAKING MEDICAL BAD NEWS IN OPHTHALMOLOGY ESPECIALLY IN DIABETIC RETINOPATHY

Henriette PUSZTAFALVI[1], Lívia TÓTH[2], Orsolya MÁTÉ[3]

ABSTRACT

Aim: Characteristics of health care professionals to report bad news and the conditions of communication at the Ophthalmology Clinic of the University of Pécs, among diabetic retinopathy patients. Data and methods: Quantitative and cross-sectional examination, 2018. Statistical methods: descriptive and mathematical statistics (χ2-test). Results: Most of the examined medical professionals (90.90%) are not able to rely on a protocol by breaking bad news, however, the need for a protocol is formulated as more than half of the respondents (59.09%). Conclusions: Health care professionals would need to develop a protocol to report bad news in health care institutions, also in the Department of Ophthalmology, furthermore, attention should be paid to improving the various circumstances during providing information to patients.

KEYWORDS

bad news, breaking bad news, protocol, diabetic retinopathy

INTRODUCTION

In Hungary, diabetes is a common disease of the population. According to the data of the Hungarian Central Statistical Office the 627.1 diabetics / 10,000 inhabitants registered in 2003 doubled by 2017, because according to the lates data 1321.4 diabetics / 10,000 inhabitants live in Hungary. [1]. 90% of patients take medication for this health problem (including insulin shots). Diabetes has a lot of negative effects on health status, the most serious complications is diabetic retinopathy, which can lead to severe vision loss and even complete vision loss. Diabetic retinopathy is responsible for 1.0-4.8% of blindness worldwide [2]. According to the Wisconsin Epidemiologic Study of Diabetic Retinopathy [3], if diabetes mellitus has existed for more than 15 years, then almost all patients develop some form of diabetic retinopathy. Total vision loss occurs in 14-20% of diabetic patients aged 65-74 years. The incidence of retinopathy in Hungary is 6-14% per year. The annual incidence of diabetes blindness in the years between 1996-2000 in Tolna and Győr-Moson-Sopron counties was 16.3% and 16.6% according to a blindness survey [4]. Communicating visual impairment and the possibility of loss of vision can be a serious stress for the patient and also for the healthcare staff. The bad news does not only make the patient's life harder, but it can also affect their

[1] Dr. Henriette, Pusztafalvi Univesity of Pécs, Faculty of Health Sciences, Institute for Health Insurance, Department Health Promotion and Public Health
[2] Lívia Tóth Univesity of Pécs, Faculty of Health Sciences, Institute for Nursing Sciences, Basic Health Sciences and Health Visiting
[3] Dr. Orsolya Máté Univesity of Pécs, Faculty of Health Sciences, Institute for Nursing Sciences, Basic Health Sciences and Health Visiting

environment. In patient care we call bad news is any news that "drastically and negatively changes the patient's life vision" [5]. Negative news, even with the best intentions and after the most careful communication theoretical and practical preparation, shock the patient or the relative, and it is important that the information provider is aware that the receiver will remember what happened during the communincation until the end of his/her life [6]. An important prerequisite for effective patient care is communication between the patient and the physician, and it's special case is informing and educationg the patient about the status and treatment. Anxiety, which can be significant among newly diagnosed patients, can negatively affect the information processing and decision-making ability of patients. Too much, new information of the disease can further increase the level of anxiety, in addition, a further complicating circumstance is that physician-patient communication usually takes place in a stressful environment. Most physicians emphasized the role of human factors, namely, communication skills, empathy and human knowledge [7]. The way in which the health care staff communicates bad news basically influences how well patients are able to understand their real health status and adapt to it. Based on the opinion of health care professionals, it would be necessary to develop a protocol that helps them communicate bad news. Besides developing the protocol, it is essential to develop communication competence among health care professionals [8]. Even though visual impairment has a significant impact on our society, however, there is only a few studies on how to communicate bad news to patients who lose their vision, as there is no protocol developed for this purpose in Hungary. In Hungary, under the Law CLIV. 1997 only physicians of health care professionals are entitled to report bad news until now, but based on a new Regulation from 2016, nurses who started their education in the newly launched advanced practice registered nurse Master's degree programme in the autumn semester of the academic year 2017/2018, will also have the qualification to communicate bad news. This is a big step forward, as several foreign researches proved that nurses have an extremely important supporting role during communication [9]. The aim of this research was to assess - in the context of a pilot study - conditions for reporting bad news at the Department of Ophthalmology at the Clinical Centre of the University of Pécs, the attitude of health care professionals and the communicational experiences of patients with diabetic retinopathy.

Material and method

The study included 22 health care workers and 103 newly diagnosed DR patients. We excluded those health care workers from the research who spent their period of notice during our research and patients who have previously been diagnosed with diabetic retinopathy. Data were processed using SPSS 20.0 statistical software, descriptive statistics, and □2 testing. Our statistical results were considered significant at $p < 0.05$.

Results

Healthcare professionals' opinion on communicating the bad news

Our research revealed that most of the interviewed health care professionals are unable to rely on a protocol regarding sharing bad news, as 90.90% (n = 20 person) at the Department of Ophthalmology of the University of Pécs do not know that there would be a protocol for it. Nevertheless, more than half of the staff at the Department of Ophthalmology (59.09%; 13 person) would find it helpful or would like to have such a protocol developed. Half of health care professionals believe that developing the protocol is the competence of an ophthalmologist.

More than half of health care professionals received training in communication (86.4%; n = 19) during their studies, most of those were theoretical (57.89%). Less than half of the respondents (45%; 10 person) learned about communicating bad news during communication

training, more than half of the respondents (54.5%) did not learn how to break bad news in any form. Healthcare workers who met with bad news communication during their studies they mostly (45.5%) met it during their higher education studies, within 5 years after they started working (27.3%). 63.6% of the respondents said that it would be very important for them to be able to gain knowledge about bad news within a training. There was a significant correlation between educational attainment and participation in sharing bad news ($p = 0.014$). Those who participated in higher education are more likely to report bad news (27.3%) than those with secondary education (13.6%). Based on the results, the respondents said that it was extremely important to fully inform patients (86.4%; $n = 19$). The team's preference for presence was as follows: professionals said that the presence of relatives was considered more important than nurses', but nearly 60% of them thought it was essential to support relatives and patients by nurses. 90.9% of the respondents consider it important that a couple's other member participate when sharing bad news, and according to 72.2% the presence of relatives would make the communication easier. Existing experiences show that more than 90% ($n = 20$ person) of health care workers think that patients with bad psychological functions make communication difficult, and they think that low intellectual ability can be an obstacle. Each respondent ($n = 22$ person) would find it helpful to provide a separate room for sharing bad news. According to the respondents, the most optimal time would be immediately after the condition occurs (86.4%), with the elimination of timelimit (95.5%) and objective style (72.7%), at the request of the patient repeated several times (90.9%).

Patients' - who are diagnosed with diabetic retinopathy - opinion on communicating the bad news

During providing information for treated patients 93% (96 person) of them received bad news according to their health status. In most cases, an ophthalmologist (84.5%) reported the diagnosis, and 11 (10.7%) were residents. Between the occurrence of the condition and the communication, one hour passed for 27 people, 24 hours for 20 person and 40 people could not determine the exact time.In 93% (92 people) of the cases the venue of the communication was a specialist's practice and 5% received the bad news in the corridor. Almost 50% (53 person) reported that there was a nurse and 49% (50 person) that relatives as well. Nearly 65% said that the presence of the spouse / partner had a determinative role. In the case of female patients, there was a significantly higher demand for the presence of other family member ($p = 0.002$) during the communication, than for men. Based on their preferences only 13% considered the presence of a nurse more important than their relatives'. 36.9% of the interviewed patients felt that the health care professional emphasized positive things the most. According to the answers of the respondents, the most most typical characteristics were helpfulness (57.3%, average 2.13, $SD = 1.493$), which was considered more significant by people with higher education than patients with lower secondary education ($p = 0.013$). The vast majority of patients were satisfied (56.3%, mean: 2.13, $SD = 1.493$) with communication, as 52.4% of patients (average: 2.25, $SD = 1.526$) reported it helped them to accept their status. Patients with a higher level of education than secondary were significantly more satisfied with the provided information ($p = 0.039$) than those who had lower education level than secondary. (Table 1)

	Education level lower than secondary (elementary school, vocational)	Education level higher than secondary (college, university)	
Emphasizing positive things about the disease by the communicator	32%	52%	p=0.004
Helpfullness during the communication by the communicator	29%	48%	p=0,013
Satisfied with the performance of the communicator during his/her tasks	29%	50%	p=0.003

Table 1: Relations between the educational attainment of patients and the oppinion on communication

Mostly despair (average: 3.68), hopelessness (mean: 3.67, SD = 1.309), anger (average: 3.87, SD = 1.326) and indecision (mean: 3.58, SD: 1.347) appeared among patients.
Among patients who were satisfied with the answers to their questions during the reporting, the feeling of anger was significantly lower, than those who were not satisfied with the reporting ($p = 0.025$). Patients who reported feeling anxiety rated the communicator's performace significatly worse ($p = 0.043$). Female patients had a significantly higher proportion of anger towards the communicator, than male ($p = 0.046$). According to the majority of the interviewed patients (90.29%, n = 93 persons), they had the opportunity to ask questions when they were informed and afterwards they could contact the department's professional staff (77.67%, n = 80 person). Most patients (67%, n = 40 women, and n = 29 men) have been contacted a physician specialist for advice. Following the information, the majority of patients (63.11%, n = 65 person) considered that they had enough time to talk about their condition, however, who had hogher education level than secondary significantly felt like they needed more time ($p = 0.041$). Patients who were satisfied with the length of the information time said they were able to understand the information in a higher percentage ($p = 0.007$). 46.6% of the respondents (n = 48 person) received some written information about their disease, which was considered appropriate by 47 of the patients, and understandable also by 47 people. Patients who did not received written information gave significantly lower scores during the evaluation of news reporting ($p = 0.013$). When asking what kind of help would they have needed, the majority of patients responded with "professional communication" (44.7%, n = 46 person), 41 responded information and 16 the help of a specialist. In the figure below, we compared the optimum conditions during communication with the opinion of healthcare professionals and the conditions that were present at the time of communication on patients' opinion. (Figure 1)

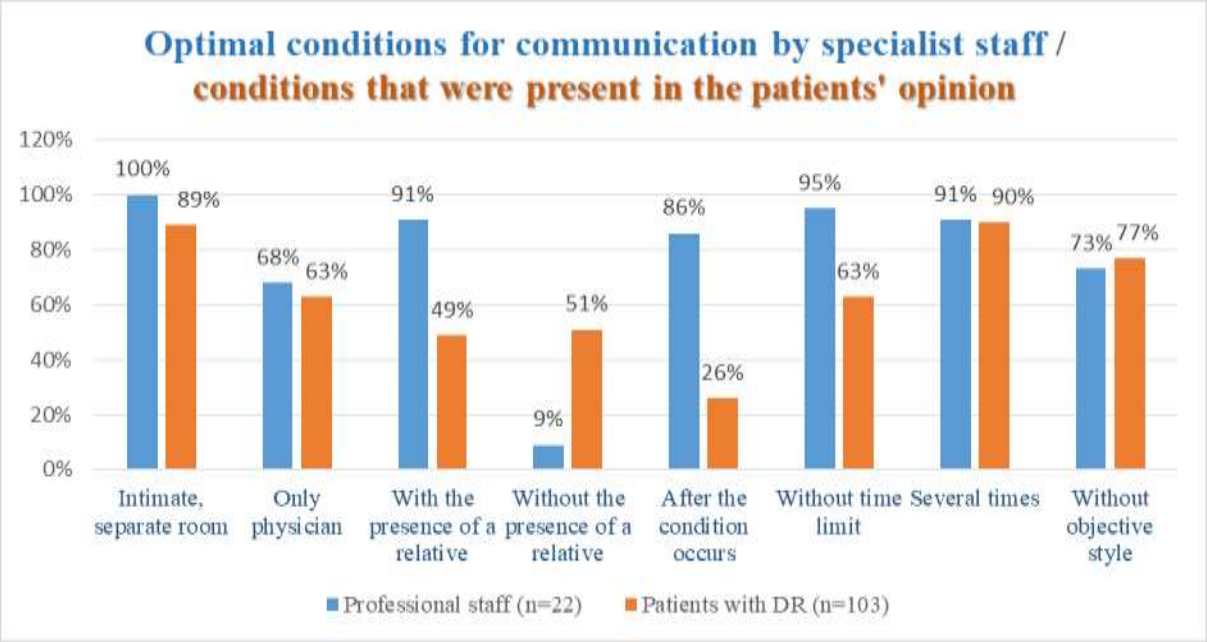

Figure 1: Communication's optimal conditions according to the professional staff compared to the present conditions during communication on patients' opinion

SUMMARY

As it can be seen, healthcare staff have unanimously stated that a separate room plays a very important role in the communication, but based on the experience of the patients this has not always been the case. 91% of physicians and nurses considered the presence of a relative to be important, but only 49% of the patients said they were present. In the opinion of 86% of healthcare professionals, the time between the occurrence of the condition and the communication should be minimal, about 1 hour, nevertheless, only 26% of patients reported that it happenned like this and information was provided within 1 hour after the occurance of their condition. 95% of physicians and nurses think that information should be provided without any time limit, leaving enough time to answer the questions that arise, however, only 63% of the patients felt that they had enough time during the information. 91% of health care workers think that in case of bad news, patients have to be given the opportunity to clarify their issues several times, and to find peace of mind about their concerns. Our research shows that healthcare professionals are striving to comply with this, as 90% of patients felt that they had the opportunity to discuss their problems several times with their treating physician.

CONCLUSIONS

Our research revealed that, in line with what has been reported by Horwitz [10] and Mozaffarieh [11] the majority of respondents think that it is the best to report bad news immediately after the condition occurs. Pateints preferred to be informed undisturbed at the doctor's practice, in the presence of a spouse or nurse, which are in line with what is proposed in the Skotko research [12], and the same result is coming out from this research that the various distracting factors also have a negative impact on the assessment of the quality of communication by patients. The length of sharing news positively increased information satisfaction, and the understanding of the provided information was also higher among patients who thought they had enough time to talk about their condition. Like the suggestions of studies published

by Rimmerman and Hofer [13], interviewed healthcare workers in all cases consider it optimal to provide information to patients in a separate room, in the presence of a spouse, immediately after the condition occurs, without time constraints and objective style, repeated several times. From our data it turned out that, similarly to the research published by Németh at al. in 2016 [8] the role of nurses is particularly important in reducing negative feelings after the communication. In the vast majority of cases, the nurse is present when the bad news is shared, in fact, in the case of some patient, the most important role was attributed to the nurse during the communication. These data all prove the validity of the advanced practice nurse master's education, where the information provider is the same person as the nurse.

The results of this research coincide with international publications from the last 25 years [14,15,16] that a protocol developed for sharing bad news in this institution would greatly contribute to facilitate the work of health professionals, as this is one of the most stressful tasks for them. Respondents entrust with the elaboration of the protocol primarily ophthalmologists or psychologists.

Data revealed that, similarly to the published study in 2014 by Máté at al. [17], less than half of health workers learned how to share bad news within communication trainings, and more than half of the respondents did not learn about it in any way during their career. Based on these, in addition to the development of a protocol, it would be useful to introduce a communication training for healthcare workers that will help increase their effectiveness in communicating bad news, to help the situation of physicians and patients as well, which has been proposed in international literature approximately for 20 years now [10,18,19] and published in the ophthalmic area [20]. Our research revealed that participants in the survey strongly support the inclusion of official communication training in the education of ophthalmic residents, which facilitates the communication of bad news, in agreement with the publications of Zakrzewski at al. and Spafford et al [21,22].

In summary, besides the protocol of sharing bad news, it would be important to acquire different theoretical and practical communication skills in order to solve communication situations and to make communication efficient. Special trainings could provide effective help to health care staff to implement the quality of the communication and to fulfill their task to the maximum.

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