

Patients' Perceptions of Receiving a Diagnosis of a Hematological Malignancy, Following the SPIKES Protocol

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Abstract—Objective: Sharing devastating news with patients is often considered the most difficult task of doctors. This study aimed to explore patients' perceptions of receiving bad news including which features improve the experience and which areas need refining.

Methods: A questionnaire was written based on the steps of the SPIKES model for breaking bad news. 20 patients receiving treatment for a hematological malignancy completed the questionnaire.

Results: Overall, the results are promising as most patients praised their consultation. 'Poor' was more commonly rated by women and participants aged 45-64. The main differences between the 'excellent' and 'poor' consultations include the doctor's sensitivity and checking the patients' understanding. Only 35% of patients were asked their existing knowledge and 85% of consultations failed to discuss the impact of the diagnosis on daily life.

Conclusion: This study agreed with the consensus of existing literature. The commended aspects include consultation set-up and information given. Areas patients felt needed improvement include doctors determining the patient's existing knowledge and checking new information has been understood. Doctors should also explore how the diagnosis will affect the patient's life. With a poorer prognosis, doctors should work on conveying appropriate hope. The study was limited by a small sample size and potential recall bias.

Keywords—Communication, diagnosis, hematology, patients.

I. INTRODUCTION

THE term 'bad news' can have many meanings; in the medical context it is understood as new information that causes an adverse change to a person's expectation of the future [1].

For many healthcare professionals sharing bad news with a patient is a challenging, yet frequent task [2]. Historically, it was considered good practice for doctors not to disclose bad news about a diagnosis to patients [3]. However a 1996 study found patients wanted to know not only their diagnosis but information about treatment options and prognosis [4]. It is now accepted that patients have the right to all information they desire about their diagnosis [5] and therefore debate has moved on the best method of sharing the news. Conveying bad news effectively leads to an improved patient response [6].

Due to lack of education [7], less experienced doctors often feel unsure about how to break bad news [5]. Aiming to offer guidance when breaking bad news, several protocols have been developed that comprise the commonly accepted

principles. The first intrinsic principle is to be honest with the patient. This shows respect for the patient's autonomy and is essential for the patient to give informed consent to any future procedures [3].

While the best location to deliver bad news may be under dispute, there is overwhelming consensus that the news should be given to the patient in person and not via telephone or e-mail [8], [9]. It is becoming common for doctors to elicit any existing knowledge the patient may hold [5] and this can be used to construct an appropriate discussion for the individual. It is also useful to find out the level of information the patient would like to know; an important principle is to ensure that the patient receives the amount of information they find suitable [4]. Another idea designed to improve the patient's response is to give the patient some warning of the subsequent bad news, this helps to prepare the patient [10].

A very important principle of breaking bad news is to encourage and respond to patient emotions [5]. Moreover, it is equally important to identify denial from the patient and respect it as a method of protection [4]. In all cases, but especially when the patient experiences denial, the doctor should give the patient time and allow them to decide the pace of the discussion [10].

Finally, conveying hope in some form is beneficial to the patient. Although it is sometimes inappropriate for doctors to be optimistic about a cure, this principle also includes being hopeful for other unrelated events in the patient's life [4].

The current models for breaking bad news are based on these principles that have derived from expert opinion and experience [2]. One model describes healthcare professionals as either: "blunt and unfeeling", "kind and sad" or "understanding and positive", with the latter being the best at delivering bad news [6]. This type of clinician would meet all the basic principles more closely than the other two and so doctors should aim to portray this example. Possibly the most known protocol for delivering bad news in the oncology setting is the SPIKES model (see Table I). This six-step protocol, used as guidelines in America [2], comprises many basic principles while producing a structure for clinicians to follow.

The main aim of this study was to learn the theory behind breaking bad news and discover patients' perceptions of receiving bad news in the haematology setting; including what they thought was done well and areas that could be improved. The study was designed following the SPIKES protocol because it comprises the basic principles and provides a

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structure. There is an ever increasing amount of literature available surrounding this topic. Yet, there is a noticeable lack of research concentrating on the experience from the patient's view [9]. Conducting a literature search of topic returns many results worldwide but few from the UK and few for haematological cancers specifically. This study will improve the evidence base for both fields. Furthermore, the SPIKES model has only been evaluated once in Europe despite its popularity [2] so it would be useful to assess how closely it fits with methods currently being used in the UK. With a limited evidence base, institutions may be ill informed when making decisions about education in this area [11]. One of the few studies conducted in the UK found that 40% of patients weren't satisfied with the delivery of the bad news [9]. Due to this and the importance of the issue more research is worthwhile.

TABLE I
THE SPIKES PROTOCOL [3]

Step	Explanation
S Setting up the interview	This step involves selecting a private environment, ensuring the patient feels comfortable and the people that are present
P Patient's perception	This step involves asking open question to assess the patient's current knowledge. It can also help the doctor to discover the patient's thoughts and feelings.
I Patient's invitation	This step is concerned with finding out how much information the patient would like at that time. The doctor can also find out the best way to convey the information to the patient.
K Knowledge	This section of the model involves the transfer of information to the patient. The level of information and use of vocabulary should be tailored to the individual patient. Doctor should try to be sensitive and it is very important for the doctor to check the patient has understood the information.
E Emotions	In this part, the doctor should recognize and respond to the patient's emotions. This involves showing empathy. This step should be used throughout the consultation.
S Strategy and summary	The final step involves creating a plan that both parties agree to, this could be a prognosis, a treatment plan or a plan to meet for a further consultation.

It is expected that this study will increase the evidence base on how bad news is delivered from the patient's perspective. The study will also show which features improve patients' experience and how well they are currently being performed. The findings could suggest how easily guidelines based on the SPIKES model could be implemented.

II. METHODS

To begin, some background reading was done through recommended resources and a literature search. The questionnaire was written based on the steps of the SPIKES model. The questions were divided into sections. The first section titled 'patient demographics', aimed to elicit personal information without comprising anonymity. The next six sections represented the six steps of the SPIKES model. The questions in these sections were derived from the directions of the model. The first section comprised questions about the environment and people present. This was followed by a section based on what the patient thought of the consultation.

Next, the patient invitation section tried to determine what the patient wanted from the discussion and the extent to which it was met. The knowledge section determined how appropriate patients found the amount, depth and delivery of information. The final section, concerned with the structure of the consultation, allowed patients to rate the experience in terms of the doctor's communication skills.

There were a mixture of qualitative responses and multiple choice answers; however the participants were always able to give qualitative responses if they felt there were no multiple choice answers that represented their views.

The participants were asked the questions by interviewers, who documented their answers. The interviewers were also available to explain the questions to the participants. The questionnaire was attempted by 20 participants who were in/out patients at Arrowe Park Hospital.

The inclusion criteria for participation comprised a diagnosis of a haematological malignant disease and treatment for the disease at this hospital. Additionally, it was essential the patients gave voluntary and informed verbal consent.

III. RESULTS

Due to help from the interviewers, all of the 20 questionnaires attempted were completed and used in this study. Of the participants, 55% were male, 45% were female and their ages ranged from '18-24' to 'over 75'; 70% of the participants were 55 years or older (Fig. 1).

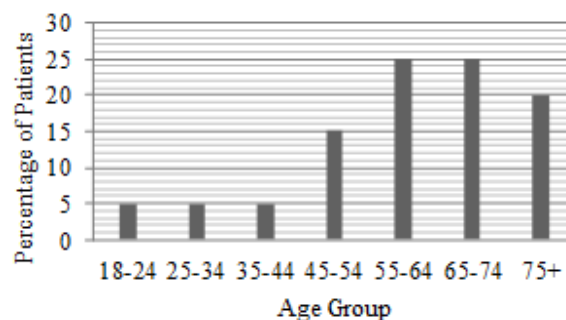


Fig. 1 Age Distribution of Patients

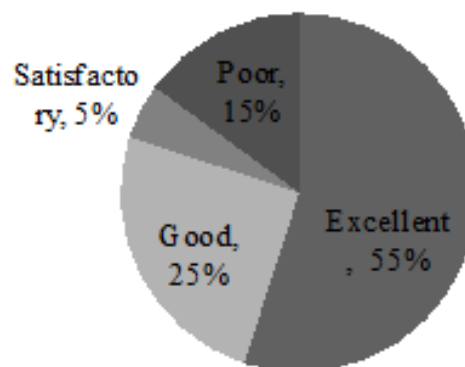


Fig. 2 Patients' ratings of the consultation

All of the patients spoke English as their first language. All diagnoses were made between 2002 and 2014, 55% of diagnoses were made within the past year. At the time of the diagnosis, the majority of patients had a stage one cancer, with a few patients at stages 2, 3 and 4. The participants rated their experience: 55% said 'excellent'; 25% reported 'good'; 5% said 'satisfactory' and 15% stated 'poor' (Fig. 2).

'Poor' was rated more commonly by women and participants aged 45-64. Those who received their diagnosis within the past few years tended to have a better consultation. The stage of the cancer at diagnosis didn't seem to affect how the patient rated the consultation.

Step 1. All patients felt the setting of the consultation was private; the majority received their diagnosis at hospital. Only one patient reported an interruption during the consultation. Of the patients that rated their experience as 'poor', all consultations took place with doctors, nurses and a relative present. While patients who rated their experience as 'excellent' had both doctors and nurses present in 55% of cases and a relative present in 73% of cases. The majority of patients who had relative present found it useful; the main reasons for this were additional support and having someone to help remember information.

Step 2. Of the patients in this study, three quarters said they received the correct amount of information in the diagnosis consultation. However only 35% of patients were asked what they already knew about the condition before the doctor gave the information; all patients who rated their experience as 'poor' denied being asked, while 55% of patients with 'excellent' consultations were asked. 25% of patients left the consultation with questions they hadn't asked, for the 'poor' consultations this was mainly due to feeling shocked. The patients reported a range of initial emotions (Fig. 3); the most common was shock with 45% of patients stating this. 'Fear' was only experienced by patients who described their consultation as 'poor'. Overall, most patients found telling relatives and the possibility of death the most devastating aspects of the news. The majority of patients who rated the consultation as 'excellent' were expecting bad news and knew the reasons for the tests/scans as opposed to a minority of those who described it as 'poor'.

Step 3. 85% of patients felt they were told everything they wanted to know but 25% found some information confusing. Patients who had a 'poor' consultation reported finding the information confusing more than those with an 'excellent' experience did. Additional information such as leaflets were given to 75% of patients; of those who received additional information 87% found it useful. Only 20% of patients in this study were shown x-rays/diagrams but the majority of these patients found them useful. No patients who rated their experience as 'poor' were shown visual aids.

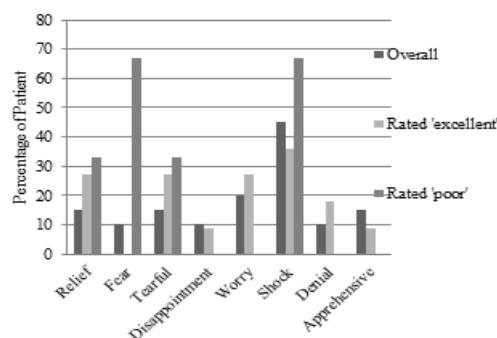


Fig. 3 Initial emotions reported by patients

Step 4. After the diagnosis was shared with the patient: 95% of patients remember discussing the diagnosis; 75% remember being told information about the illness; half of patients remember discussing treatment options; a quarter of patients remember being told about possible side effects of such treatments and 55% said they remember discussing prognosis. Patients claiming they had better experience also tended to remember discussing more of these areas? After this initial meeting, 20% of patients revisited the doctor to clarify information. No patients who had a 'poor' experience revisited the doctor whereas 27% of those with an 'excellent' experience did. All patients agreed the doctor's language was clear but only 25% of patients were asked if they understood the information. Most patients felt the doctor delivered the information sensitively. All patients with an 'excellent' consultation said the doctor conveyed the information sensitively, appreciated their views and checked their understanding of the information; however no patients with a 'poor' experience agreed any of these features were true of their doctor. Similarly, 100% of 'excellent' consultation patients felt the doctor was listening and responding to them as opposed to 33% of 'poor' consultation patients.

Step 5. Overall, the majority of patients felt reassured after the meeting and agreed the doctor conveyed hope. This was especially true for patients who gave an 'excellent' rating, the main reasons given were having a diagnosis and treatment plan; many patients also mentioned the belief they had in the doctor. Conversely, of those who had a 'poor' experience, only 33% felt reassured and none claimed the doctor gave hope. This was mainly due to feeling shocked and the doctor giving a poor prognosis without hope. More discrepancy was found when asking the patients the most helpful aspect of the consultation. Of the 'poor' consultations, the most helpful aspect was being referred to various places whereas in 'excellent' consultation, it was the positivity and hope conveyed by the doctor. Most patients felt the doctor spent enough time with them. In the better consultations, counselling was offered more frequently.

Step 6. Upon leaving the consultation, 90% of patients had a

plan they agreed to. A prognosis was given to 55% of patients. A prognosis was given more frequently in 'excellent' consultation than 'poor' consultations. Doctors only explored the impact the diagnosis would have on other aspects of the patient's life in 15% of cases; this was 18% in 'excellent' consultation but zero in 'poor' consultations. To conclude the questionnaire, the patients were asked to offer any suggestions to improve the experience. Overall the most common suggestion were to offer lots of information and for doctors to be more sympathetic towards the patient. Additionally, patients with a 'poor' experience said doctors should give more hope even with a regrettable prognosis.

IV. DISCUSSION

Firstly, step 1 was done well from the perspective of most patients in this study. All patients were told their news privately, in person. Previous studies assessing patients' preferences found that being told face to face in an undisturbed atmosphere was extremely important to patients during bad news consultations [2], [9]. The one reported interruption could have been avoided if telephones were silenced. This study opposed the findings of research conducted in 2009 which concluded patients thought having their relatives present a less concerning issue [9]. However, the majority of the patients in this study who were accompanied by a relative found it useful. Therefore, to improve this step, patients should be advised to bring a relative/friend with them to the consultation.

There are some improvements that could be made to step 2. The majority of patients who claimed to have 'excellent' experience knew why they had undergone various tests. Because of this, more of these patients expected bad news and this may have been why less reported feeling shocked and improved their perception of the consultation. An article published in *The Lancet* suggested the need for continuity of information during cancer care [12]. This could be extended further to the investigation stage, which could better prepare patients while making consent to such investigations more informed. Another element of step 2 which could be developed is the doctor asking the patient what they already know. In this study, asking the patient improved the quality of the consultation from the patient's perspective. No patients reported they received too much information but some did say they would have liked more. A previous study found that most patients were disappointed they didn't get an explanation of the course of the disease, as they knew least about this [2]. By determining the patient's existing knowledge, the consultation could be tailored to the individual to provide the knowledge they currently lack. It also allows the doctor to correct any misconceptions and determine if the patient is experiencing denial³. Doctors should also elicit what information the patient would like to receive [2], then more patients would be told everything they want to know, improving step 3.

The initial responses reported in this study highlight the effect bad news delivery can have. 'Fear' was only felt by

patients who had a 'poor' consultation. This supports many previous studies who found how well the news was delivered affected the patient's emotions and adjustment to the illness [2], [6]. The stage of the cancer at diagnosis had no effect on the overall rating patients gave to the consultation, despite doctors finding it more difficult to deliver the news when the prognosis is worse [3], again showing the importance of effective delivery.

In step 3, the distribution of additional information such as leaflets was popular with patients. One paper, that only used secondary research, suggested that bad news consultations should be recorded for patients to refer back to [13]. This idea was disliked by patients in this study, although there was more support from those with a better consultation. Only a small minority of patients were shown x-rays/diagrams during their consultation, however of those patients, most agreed seeing them was useful. Although unmentioned in most papers, one did suggest asking patients their preference in receiving information can help understanding [13].

For step 4, this study found most patients only needed one consultation to receive the information. A similar study found that patients are so shocked when given the information they struggle to remember what they are told so two discussions are required; this research only used a small sample size which may not represent the true population². Patients should be offered a second consultation and information should be provided continuously throughout the illness [12].

Step 4 highlighted the greatest difference between 'excellent' and 'poor' consultations indicating the need for this step to be standardized. The better consultations comprised a sensitive doctor who checked the patient's understanding while listening to the patient and appreciating their views. The most common suggestion for improvement was for doctors to be more sympathetic. In one study, patients preferred doctors to be sensitive by their choice of words and tone of voice, although this study had a high female to male participant ratio and may not be representative [6]. Another study found that it is very important to patients to have all their questions answered properly⁹. From this study, it seems by improving step 4; the number of 'poor' ratings could be reduced.

In step 5, most consultations, but especially those rated 'poor', could be improved by more reassurance and hope from the doctor. This finding supports a study which found only a minority of doctors gave reassurance and hope [6]. A study focusing on doctor's experiences found that giving hope to patient whilst being truthful is the most difficult part of breaking bad news [3]. Because this seems to be a problem for doctors and important to patients, the issue should be addressed in undergraduate education.

In step 6, the majority of patients had a plan when they left. This is very important because patients with a plan tend to be less fretful [3]. However, exploring the other aspects of the patient's life was done rarely. A common fault when breaking bad news is purposefully not picking up social cues from the patient⁴. By discussing how the diagnosis will affect the life will not only improve this step but also encourage appreciation

of the patient's concerns.

This research has limitations, the most significant being the sample size. With only 20 participants, the results are susceptible to a type 2 error if tested statistically. Our sample was particular lacking in younger patients and patients from different cultural backgrounds. Many patients can't remember all of the consultation due to the intense emotions experienced [2]. This teamed with time lapsing between the consultation and this study makes recall bias probable. Bias could also have originated from the interviewers as they explained the questions and recorded the patient's responses.

V.CONCLUSION

The research fulfilled the aim to discover patients' perceptions of receiving bad news. Overall, most patients were happy with their consultation. The areas patients particularly praised were the set-up of the consultation and how sensitively the news was delivered. The knowledge section was done well generally, however it showed the greatest difference between 'poor' and 'excellent' consultations; therefore should be improved to standardise the experience. Other areas patients felt needed improvement include the doctor determining the patient's existing knowledge and what they would like to know. With a poorer prognosis, doctors should work on reassurance and conveying hope. Most consultations could be improved by the doctor exploring the effect of the diagnosis on other areas of the patient's life. The study has increased the evidence base for the UK and haematological cancer setting.

Due to the similarities between the current methods and the SPIKES models, guidelines based on this model could be integrated relatively easily. To assess if the model appeals to doctors, a study from the doctors' viewpoint should be completed. This research did have some limitations, notably a small sample size; therefore future studies with larger and more varied patient demographics should be conducted into patients' preferences. It is possible this research contradicted past studies because patients' insights change over time; it would be worthwhile conducting a longitudinal study to explore this.

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