Breaking bad news—what patients want and what they get: evaluating the SPIKES protocol in Germany

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Background: Evaluation of the SPIKES protocol, a recommended guideline for breaking bad news, is sparse, and information about patients’ preferences for bad-news delivery in Germany is lacking. Being the first actual–theoretical comparison of a ‘breaking bad news’ guideline, the present study evaluates the recommended steps of the SPIKES protocol. Moreover, emotional consequences and quality of bad-news delivery are investigated.

Patients and methods: A total of 350 cancer patients answered the MABBN (Marburg Breaking Bad News Scale), a questionnaire representing the six SPIKES subscales, asking for the procedure, perception and satisfaction of the first cancer disclosure and patient’s assign to these items.

Results: Only 46.2% of the asked cancer patients are completely satisfied with how bad news had been broken to them. The overall quality is significantly related to the emotional state after receiving bad news (r = −0.261, P < 0.001). Patients’ preferences differ highly significantly from the way bad news were delivered, and the resulting rang list of patients’ preferences indicates that the SPIKES protocol do not fully meet the priorities of cancer patients in Germany.

Conclusions: It could be postulated that the low satisfaction of patients observed in this study reflects the highly significant difference between patients’ preferences and bad-news delivery. Therefore, some adjunctions to the SPIKES protocol should be considered, including a frequent reassurance of listeners’ understanding, the perpetual possibility to ask question, respect for prearrangement needs and the conception of bad-news delivery in a two-step procedure.

Key words: breaking bad news, spikes protocol, bad-news delivery, cancer diagnosis

Introduction

In the medical context, bad news are ‘any news that drastically and negatively alters the patient’s view of her or his future’ [1]. Bad news means a kind of information that starts a new life era for the patient. Breaking this kind of news is a frequent and difficult task for every physician, independent of her or his specialty. It is particularly common in the oncological setting that life-threatening and life-influencing diagnoses are frequently given to the patients [2, 3], such as newly diagnosed cancer or undesirable developments of a known cancer. The quality of the delivery of bad news to patients seems to be directly related to patients’ stress and anxiety, their adjustment to the bad news, coping and satisfaction with care and health outcome [4].

There are a few established recommendations for the delivery of bad news in the United States [4, 5], Australia [6] and the UK [7]. These protocols are primarily based more on expert opinion, but less on empirical evidence. Only a few studies have evaluated patient-based evidence for the recommended items and steps of these protocols. One comprehensive guideline that had been developed in Australia [5] is based on the consensus of patients, nurses and doctors. After implementation, the evaluation of the protocol in Australia in melanoma patients showed that several modifications of the protocol should be reasonable following patients’ preferences [8]. Another study evaluated the consensus between breast cancer patients, oncologists and oncology nurses on the guidelines for breaking bad news and showed, using a consensus of 70%, that there is a high level of agreement between the groups. However, there was only little consistency in the ranking of the checked items [9], suggesting significant differences between doctors’ and patients’ preferences on how to break bad news. Additionally, there is rare evidence about the adherence to these guidelines and about the impact these guidelines may have on satisfaction among patients.

The most popular guideline, the SPIKES protocol [1], recommends a six-step protocol for delivering bad news, with a special application for cancer patients [2]. It was evaluated for structuring the delivery of bad news in the United States and it had reached guideline status in America and in a number of other countries [10], including Germany [11]. It is used as a guide for this sensitive practice and for communication skills training in this context [11, 12]. The acronym SPIKES refers to six steps...
recommended for breaking bad news: (i) Setting up the interview, (ii) assessing the patient’s Perception, (iii) obtaining the patient’s Invitation, (iv) giving Knowledge and information to the patient, (v) addressing the patient’s Emotions with empathic responses and (vi) Strategy and Summary [1].

Evaluation of the SPIKES protocol is sparse and insufficient, and further studies are needed. Neither the SPIKES protocol has been evaluated in Europe before nor is there sufficient information how bad news are broken in Germany and about patients’ preferences for delivering bad news. Therefore, we conducted a survey based on the items of the SPIKES protocol and asked cancer patients how bad news had been broken to them and about their preferences for the related communication process. Being the first actual–theoretical comparison of a ‘breaking bad news’ guideline, the recommended steps of the SPIKES protocol were evaluated, each concerning patient’s preferences and the perception of how they had been realized in bad-news delivery. Moreover, emotional consequences of bad-news delivery are significantly related to the emotional state after receiving bad news.

patients and methods

The questionnaire was handed out to 350 cancer patients in an inpatient and outpatient setting of the University Hospital Marburg (UKGM) and the rehabilitation center Klinik Sonnenblick, Marburg, Germany. In addition to written informed consent, inclusion criteria required the oncological diagnosis of a malignant neoplasm, sufficient German language skills and a minimum age of 18.

ethics

The study was approved by the institutional review board of the Medical School, University of Marburg. Before participation, subjects gave written informed consent.

questionnaire

A total of 37 items of the MABBAN (Marburg Breaking Bad News Scale) [13] representing the six SPIKES subscales (Setting, Perception, Invitation, Knowledge, Emotion and Summary and Strategy) were generated [1]. The questionnaire is composed of two main parts: the first one asks for the procedure, perception and satisfaction of the first cancer disclosure according to the recommended steps of the SPIKES protocol, while the second one consists of corresponding questions asking for the importance of patient’s assign to these items. Most of the items were rated on a Likert scale from 1 (‘entirely’) to 4 (‘not at all’).

Additionally, four items concern patients’ preferences for the doctor characteristics (e.g. profession, sex, level of familiarity) and four other items had a different format (e.g. dichotomous variable). Together, these eight items were classified as ‘informative items’ and were not included in the statistical analysis of the present study. Full statistical analyses of quality criteria of the MABBAN have been reported elsewhere [13].

The Hospital Anxiety and Depression Scale (HADS) was used to measure psychological morbidity. It consists of two subscales, each comprising seven items. The subscales assess depression and anxiety separately.

results

patients

Of the 350 returned questionnaires, six were filled in incompletely. The remaining 344 were able to be used for the analysis. Main reason for answer-missing was comprehension difficulties of participants due to old age. Demographic characteristics of the study population are listed in supplementary Table S1, available at Annals of Oncology online. The age range of the participants was 20–85 years, with a mean of 58.4 years (SD = 11.8). The most common types of disease were breast cancer (27.6%), hemic diseases (22.4%) and colon rectum cancer (11%). Only 11.3% had been diagnosed with recurrent disease. The mean time since diagnosis was 24.36 months (SD = 40.28 months), and 56.6% of the participants got the diagnosis within the past year.

‘breaking bad news’ characteristics

Characteristics of the setting and the bearer of bad news are shown in supplementary Table S2, available at Annals of Oncology online. Over 50% of the patients did not know the bearer before the conversation, 70.1% did not get the following treatment from the bearer and only 42.2% are currently in contact with him (69.7% male) or her (30.3% female).

ratings of patients’ preferences concerning important aspects of breaking bad news

Of the 37 questionnaire items to measure patients’ preferences, we identified those that the participants rated the most relevant. The mean ratings are listed in the descending order of importance in Table 1. ‘Having clarity about suffering and progress of the disease’ (SPIKES 4) was rated the most important. Of the 10 items receiving the highest ratings, 5 addressed aspects of the physicians giving knowledge and information to the patient (SPIKE 4). Three items of the ‘top ten’ were designed to measure SPIKE 6 (strategy and summary, e.g. possibility to ask questions), and two items addressed aspects of the setting (SPIKES 1).

patients’ preferences compared with reality

The results of comparing patients’ preferences with the subjectively perceived reality are also reported in Table 1. The test statistics show that there are significant differences in each variable between patients’ preferences and the reality. The ratings of ‘entirely affirmation’ were significantly higher on preference side than on the reality side. The greatest difference between what patients want and what they get was in relation to getting a definite explanation of the course of disease (z = −11.600, P < 0.001, r = −0.633). Although there is obviously a high need for information, 22.6% of the patients wanted not to be involved in the following decisions by the physician, and 42.3% of the patients stated that they were not able to make important
decisions in the first bad-news discussion. More than half of the patient group (50.2%) stated that a second talk would be necessary, preferably accompanied by a relative or loved one (76.5% of the patients voted for a second talk).

relationship between demographic and medical variables and patients’ preferences

There were no differences between ‘type of disease’ and the top-10 patients’ preferences. Significant correlations were found between the ‘age’ of the patients and the need for ‘elaborate and coherent explanation of the disease’ (r = −0.123, P < 0.05) and ‘definite explanation of the course of disease’ (r = −0.186, P ≤ 0.001), indicating a pronounced need in younger patients. There were only a few significant differences between the ‘sexes’ and their preferences. Women rated getting an ‘elaborate and coherent explanation of the disease’ as more important than did men (P = 0.044). The analyses have shown that there are differences in patients’ preferences depending on the ‘educational status’ of the patients. The main differences were ‘the need for definite explanation of the course of disease’. This seemed to be of more importance for patients with lower education-levels (9–10 years of school) compared to those with high school graduation (13 years of school with the graduation ‘Abitur’) (P = 0.027) and for patients with Certificate of Basic Secondary Education (9–10 years, ‘Hauptschulabschluss’) to those with Certificate of Advanced Secondary Education (10 years, ‘Real schulabschluss’) (P = 0.045) and those with high school graduation (13 years, ‘Abitur’) (P = 0.004).

quality of ‘breaking bad news’ discussion and emotional state after receiving a bad news

Less than a moiety (46.2%) of the patients were entirely satisfied with the communication process by which bad news had been broken to them. The overall quality of breaking bad news was significantly related to the emotional state (14-item scale of different emotional states, including depression, anxiety and sleeplessness [HADS]) after receiving bad news (r = −0.261, P < 0.001).

discussion

With regard to breaking bad news, the physician–patient communication process becomes particularly a difficult task for physicians, requiring social and communicative competence, special management and responsibility. For this reason, several recommendations for the delivery of bad news has been established, the most popular being the SPIKES protocol [1] and its application to cancer patients [2]. This protocol has reached guideline status in several countries, including Germany, and is therefore frequently used for communication skills training in the context of bad-news communications. However, it is not known whether and how the elementary steps of the SPIKES protocol are represented in common bad-news discussions, and whether the protocol meets the needs of cancer patients in Germany.

The overall quality of breaking bad news (retrospectively) in the present study correlates significantly with the reported emotional state after receiving bad news (r = −0.261, P < 0.001), emphasizing the importance for a high-quality communication process in bad-news delivery. However, compared with previous studies [14, 15], in this study, cancer patients report lower satisfaction with the way bad news was communicated, as only 46.1% were satisfied with the disclosure process of their cancer diagnosis. In general, satisfaction with physician–patient communication is known to depend on different factors, including communication skills and style of the physician, physician–patient relationship as well as biomedical and psychosocial factors [3, 13, 16, 17]. However, it could be postulated that the low satisfaction in the present study also reflects the significantly high difference between patient’s preferences and the way bad news were delivered. In regard to the first 10 preferences, patients reported a highly significant difference between request and realization, pointing to considerable deficiencies in the bad-news communication process from the patients’ viewpoint. Although the study is limited by the missing information about communication skills and styles of the physicians and their approach, a guided communication process that is closer to patient’s preferences is likely to be more helpful.

Table 1. Highest ratings of patients’ preferences regarding different aspects of breaking bad news compared with experienced reality

<table>
<thead>
<tr>
<th>Item (SPIKES number)</th>
<th>Patients’ preference ‘Entirely’ (%)&lt;sup&gt;a&lt;/sup&gt;</th>
<th>M (SD)&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Reality ‘Entirely’ (%)&lt;sup&gt;c&lt;/sup&gt;</th>
<th>M (SD)&lt;sup&gt;d&lt;/sup&gt;</th>
<th>Test statistics&lt;sup&gt;z&lt;/sup&gt;</th>
<th>r</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having clarity about suffering and progress after BBN (4)</td>
<td>96.8</td>
<td>1.03 (0.18)</td>
<td>77.9</td>
<td>1.35 (1.22)</td>
<td>−7.111***</td>
<td>−0.388</td>
<td>335</td>
</tr>
<tr>
<td>Reinsurance about patients’ comprehension (4/6)</td>
<td>94.7</td>
<td>1.05 (0.22)</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Having enough time (1)</td>
<td>94.5</td>
<td>1.06 (0.23)</td>
<td>64.4</td>
<td>1.62 (0.96)</td>
<td>−9.164***</td>
<td>−0.496</td>
<td>342</td>
</tr>
<tr>
<td>Possibility to ask questions (6)</td>
<td>93.8</td>
<td>1.06 (0.24)</td>
<td>60.9</td>
<td>1.67 (0.97)</td>
<td>−9.567***</td>
<td>−0.523</td>
<td>335</td>
</tr>
<tr>
<td>Having the feeling that planned treatment is the best (4)</td>
<td>93.8</td>
<td>1.07 (0.28)</td>
<td>60.9</td>
<td>1.77 (1.11)</td>
<td>−9.539***</td>
<td>−0.526</td>
<td>329</td>
</tr>
<tr>
<td>Elaborate and coherent explanation of the disease (4)</td>
<td>93.2</td>
<td>1.07 (0.27)</td>
<td>61.3</td>
<td>1.58 (0.87)</td>
<td>−9.297***</td>
<td>−0.506</td>
<td>337</td>
</tr>
<tr>
<td>Definite explanation of the diagnosis (4)</td>
<td>89.8</td>
<td>1.11 (0.36)</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Undisturbed atmosphere (1)</td>
<td>86.9</td>
<td>1.17 (0.51)</td>
<td>63.3</td>
<td>1.87 (1.25)</td>
<td>−8.439***</td>
<td>−0.460</td>
<td>337</td>
</tr>
<tr>
<td>Involving the patient in further planning (6/4)</td>
<td>84.2</td>
<td>1.19 (0.47)</td>
<td>48.1</td>
<td>2.14 (1.27)</td>
<td>−10.194***</td>
<td>−0.565</td>
<td>325</td>
</tr>
<tr>
<td>Definite explanation of the course of disease (6)</td>
<td>82.9</td>
<td>1.21 (0.53)</td>
<td>40.7</td>
<td>2.18 (1.17)</td>
<td>−11.600***</td>
<td>−0.633</td>
<td>336</td>
</tr>
</tbody>
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*Wilcoxon signed-rank test. **Valid percentage of response option ‘entirely’. †All items are rated on a 1–4 scale. ***P < 0.001.
Following patient’s preference information (SPIKES 4: knowledge), prearrangement (SPIKES 1: setting) and physicians’ approach are of central importance, supporting the findings from previous studies [13, 18–20]. First, patients wish to gain clarity about the expected distress and progression of the disease. This is not identical to an exact prognosis or anticipated life expectation, as these specific information items range considerably lower. Secondly, the difference between patients’ request and reality was greatest in relation to getting a definite explanation of the course of disease ($z = -11.600$, $P < 0.001$, $r = -0.633$). Rather, patients’ interest refers to the expected alteration of their everyday life and course of the disease.

Clarity about the expected distress and progression of the disease, the possibility to ask questions and the reinsurance of understanding by the physician were rated next on the top of the patients’ preference list. Particularly, the high number of requests for physician’s reassurance and the possibility to ask questions emphasizes the importance to involve patients actively into the communication process. Previously, the approach ‘ask–tell–ask’ was recommended [21]. Following patients’ preferences in the present study, we suggest to change the approach to ‘ask–tell–invite to ask–reassurance understanding’. Moreover, the importance of the identification of patient’s preferences before a discussion of bad news should not be disregarded.

Although there is obviously a high need for information, 22.6% of the patients wanted not to be involved in the following decisions by the physician, with the majority being elderly men. In a study evaluating preferences of elderly patients with metastatic cancer, more than half of the patients (52%) preferred a passive role in the decision-making process [22]. On the other hand, information needs are high. Therefore, having a look into the ethical waiver debate, the observation of this high need for information with a striking number of patients who prefer a passive role in decision-making makes clear that information and decision renunciation must be differentiated. Otherwise, the low satisfaction and the reported difference between request and realization of information items might be the result of the nature and impact of bad-news discussions and the time management of delivery. In the present study, only 23.6% of patients received a second talk, reflecting the routine of bad-news delivery in a one-step discussion. Often, the information given to the patient could not be recalled and understood in the face of upsetting news, particularly if the patients are too stunned to register any further information [23]. At the end, patients may stick to the feeling of lacking information, resulting in depression, uncertainty and anxiety [24]. Interestingly, 42.3% of the patients stated that it is not possible to make important decisions during the first bad-news discussion and 50.2% wished to have a second talk, preferably accompanied by a relative or loved one. Therefore, bad-news discussions in a two-time procedure should generally be strongly recommended.

Another important scope in ‘breaking bad news’ communications related to patients’ satisfaction is prearrangement aspects [13–15]. In the present study, adequate time and undisturbed surrounding were two of the most important requests (94.5% and 86.9%, respectively), which were realized only in ~60% of the patients satisfactorily. As already recommended by the SPIKES protocol [1, 4], these findings emphasize further the distinct importance of prearrangement aspects. However, it has to be considered that insufficient realization is due not only to individual physician attitudes, but also to the changes of clinical daily life in the last years, with increasing work load and less privacy room capacity. Therefore, hospital business management has to be aware of these patient needs and should accommodate the facilities of oncology medical care.

Next to the prearrangement aspects, emotional support is one of the central concern of the SPIKES protocol. However, similar to observations in a UK cancer center [14], supportive aspects were rated considerably lower compared with information or prerequisite items in the present study, such as the possibility to be emotional (77.9%; rank 15), empathy (65.6%; rank 16) and familiarity of the physician (52.4%; rank 26). However, it could not be concluded that support aspects might be less important for a high quality of bad-news delivery, although they seem to be of less interest in patients view.

Following the results of the present study, we suggest some recommendations for a modification of the SPIKES protocol. Patients’ needs for prerequisites should be more respected and realized by the physician and the hospital management. The physician should ask for patient’s information needs and focus on the course of the disease and implications for patient’s daily life. In every step of the protocol, the physician should routinely ask for understanding of the patient and invite the patient to ask questions. Because a single communication might not be sufficient and satisfactory for the listener and because a high percentage of patients feel incapable of making any decisions after receiving bad news, we recommend bad-news communication as a two-step procedure.

There are several potential limitations of this study, including a lack of information regarding physicians’ approach and communication style, physicians’ training in communication skills and preferences for breaking bad news in a cross-cultural population. The survey was based on the recommendation of the SPIKES protocol, and therefore, other potential important aspects might be missed. Additionally, patients were asked to recall their perception of the first cancer disclosure. It is likely that their perception and emotional state have changed over time. Therefore, a longitudinal study should be carried out that includes data about physician communication skills and training.

Despite these limitations, the study indicates a clear need for the improvement of breaking bad-news communication in Germany. Therefore, some adjunctions to the SPIKES protocol should be considered, including repeated reassurance of listeners understanding, the perpetual possibility to ask question, respect for prearrangement needs and the conception of bad-news delivery in a two-step procedure.

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